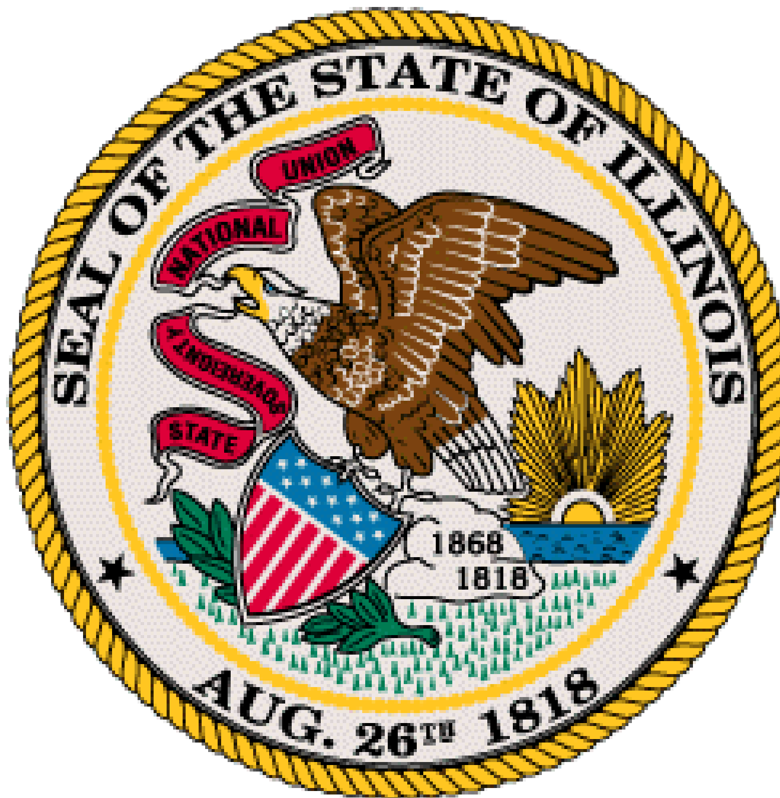
2014

State of Illinois

Office of the State Long-Term Care Ombudsman Program

For: The Illinois Department on Aging



EXPANDING THE OMBUDSMAN PROGRAM INTO HOME AND MANAGED CARE: RECOMMENDATIONS FROM STAKEHOLDERS

In August 2013, legislation passed that allowed the Department on Aging's Long-Term Care Ombudsman Program to expand into home and managed care. This expansion represents the culmination of years of hard work and effort to pull much needed gaps in service throughout Illinois. As part of this process, engagement meetings were held to gather feedback and recommendations from those that are most intimately engaged in the field. This report compiles the recommendations made by stakeholders for the expansion into home and managed care.

Executive summary

In 2012, planning began for the expansion of the Illinois's State Long Term Care Ombudsman (SLTCO) Program. In August of 2013, this expansion was approved by the Illinois legislature in the form of law, and the process of expansion was begun to expand the program from long-term care into home and managed care. In September of 2013, a report was created by Health & Medicine Policy Research Group that highlighted many recommendations for the upcoming expansion. One of which was to create a series of stakeholder engagement meetings in 7 geographically placed locations across Illinois. Six of these meetings took place and welcomed over 80 stakeholders, including nursing home administrators, members of various offices in the Department on Aging, other state departments and state representatives and their staff. The stakeholder meetings showed the anticipation and the concerns that are felt ahead of the planned expansion of the Long-term Care Ombudsman Program into home and managed care. Stakeholders openly engaged with the State on their concerns for this expansion, and suggested these recommendations:

- Clearly define the services of both the Home and Managed Care Ombudsman

- Prevent conflicts of interest within the Department on Aging and the Long-Term Care Ombudsman program by having Ombudsman and staff formally declare potential conflicts of interest upon hiring, regularly convene with Adult Protective Services and other programs as the expansion rolls out, relieve the legal conflict of interest by having multiple programs within the department sharing the same legal counsel.

- Provide additional staff to the Chicago-land region to ensure that quality services are provided before, during and after the expansion of the program as well as regionalizing the need for further staff throughout the state

- Continual, all inclusive and inner-disciplinary training for all Stakeholders, and others who wish to attend

- Continual communication and intake of feedback from stakeholders

- Regionalize and utilize the best methods for outreach for publicizing the expansion to our clients

- Carefully assess the need for data collection in regions of the state for possible improvements to the types of data collected by the Department on Aging; as well as the best way to utilize that data

- Track and measure the performance of the expansion as it rolls out for benchmark success in the hopes of more future funding, as well as the continual creation of grants and proposals for additional funding.

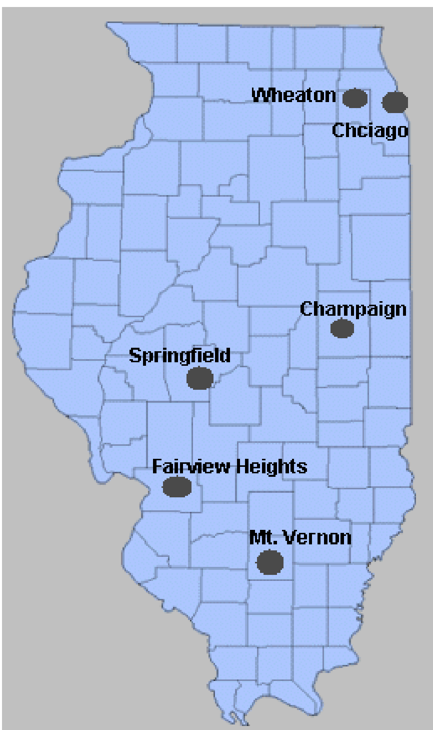
These recommendations were reiterated throughout the state almost universally by stakeholders, and represent the combined input of many individuals, and are presented in full in this report.

Introduction

In 2012, planning began for the expansion of the State Long Term Care Ombudsman (SLTCO) Program. In August of 2013, this expansion was approved by the Illinois legislature in the form of law, and the process of expansion was begun. In September of 2013, a report was created by Health & Medicine Policy Research Group that highlighted many recommendations for the upcoming expansion. Recommendation number 5 stated:

> "Develop a stakeholder engagement plan, with support from the Illinois Long-Term Care Council, and disseminate to all stakeholders. The stakeholder engagement plan should include the SLTCO (State Long Term Care Ombudsman) meeting with DOA, HFS and DHS to differentiate the LTCOP from other related programs and services"

This plan to engage stakeholders was instituted in the form of 7 stakeholder meetings. These meetings were geographically divided into 7 different regions throughout Illinois. The first, in Mt. Vernon was held at the Mt. Vernon Convention center on December 5th and saw 12 stakeholders. Springfield hosted the second meeting, occurring on December 17th at the local Area Agency on Aging, welcoming 19 stakeholders. The next day, a third was held in Fairview Heights, which saw 10 stakeholders. The fourth meeting in Oak Park Illinois was canceled due to extreme weather conditions on January 7th. The fifth stakeholder meeting was held in Chicago on January 8th, at 2102 W. Ogden in the heart of the city; this meeting saw 10 stakeholders.



Next, a meeting in Wheaton took place on January 10th, and welcomed 14 stakeholders. The final meeting was held in Champaign on January 15th, and saw 18 stakeholders. In all, there were over 80 stakeholders that attended the 7 meetings. These stakeholders included members of the Ombudsman program (local, regional and state Ombudsman), members of HFS, DOA and APS, local members of Area Agencies on Aging, county health officials as well as members of senior services and even Illinois representatives and their staff. Because of the diverse professional background of those that attended, the stakeholder meetings yielded a great trove of information and recommendations for the expansion.

These recommendations were consolidated for this report, and are presented as a whole. Many of the same issues and themes were discussed at these meetings, showing that while specific concerns were regionalized, there were several concerns that were mentioned state-wide. These included the need for clarification of the roles and services of the new Managed Care and Homecare Ombudsman additional training and concerns for funding. The presence of these issues at each meeting showed that there are universal concerns from stakeholders related to the expansion of the program. But overall, the meetings were welcoming, engaging and informative. There is excitement about this expansion, but there is also concern. This report is a reflection of those concerns. Within this report are the recommendations given to the SLTCO office for the best ways to expand the program. This report includes direct recommendations from stakeholders, as well as direct quotes from these meetings. It is structured into 3 parts.

The first part consists of “structural” recommendations. These are recommendations that pertain directly to the STLCO office and the LTC program. These recommendations are specifically addressed to current policy and plans made by the SLTCO.

Next, there are “institutional” recommendations. This consists of the recommendations that were made by stakeholders for the department as a *whole*, including senior services and APS (Adult Protective Services). These are recommendations for changes within the agency to compliment the expansion into managed and homecare, and try to address other program concerns besides just the LTC program.

Finally, there are “resource” based recommendations. These are recommendations that are based solely on the financial and technological needs of the expansion, and the concerns raised by stakeholders as we move forward.

Each of these sections has been crafted individually, as each section takes on its own set of challenges that the SLTCO, the Department on Aging and indeed the state of Illinois will face when moving forward. But no matter what the issue is or what the recommendation made is, it is critical to remember that these ideas originated from those that work in the field, and on the ground level of this program. They will be the first to feel the impact of the expansion, and it is their feedback that is critical to the survival of the expansion. This report is presented in part to them in thanks for their time and feedback, and in part to the Department on Aging in the hopes that these recommendations will be upheld.

Table of Contents

Introduction………4

Structural Recommendations………………………………………………………………………………………..8

Definition of Scope and Services……………………………………………………………………………..9

Conflicts of Interest…………………………………………………………………………………………………13

Staffing…….16

Institutional Recommendations………………………………………………………………………………..19

Training…….20

Communication………………………………………………………………………………………………………..26

Publicizing the Expansion……………………………………………………………………………………….29

Resource-Based Recommendations…………………………………………………………………………..33

Data Collection……34

Funding…….39

Conclusion……….42

Quick Reference to Summary of Recommendations…………………………………………………….44

Structural Recommendations

Definition of Scope and Services

Of the concerns expressed over the course of these meetings, there was no greater call for clarity than with the scope of services and roles that will be provided by the Homecare and Managed Care Ombudsman. This issue is the primary structural challenge facing the expansion of the Long-Term Care Ombudsman Program. It is also why it is listed at the first recommendation. This was critical not only for the personal clarity and understanding of those engaged, but was needed to help answer other issues like avoiding potential conflicts of interest, areas of training and staffing needs. While these details are forthcoming, the issue of what exactly the services of the Homecare Ombudsman and Managed Care Ombudsman will be providing, as well as how they will interact with the Long-Term Care Ombudsman program and with other areas of the Department on Aging are critical topics to address. In addition, providing these details is critical to giving a clear and concise message to clients. As one stakeholder stated in the first meeting in Mt. Vernon, "the devil is in the details, and we don't have the details yet." In a facility, the role of the Ombudsman is very clear, and well understood. But moving this program into the managed care and community setting will be a great challenge for the roles and services being provided. But in the absence of defined roles and services, stakeholders still offered their ideas on how to best solve this issue.

Starting with the Managed Care Ombudsman, stakeholders directly addressed what could potentially be a good service to provide. Managed Care Organizations are often complicated to interact with. Seldom does any one person know all the fine details of working with managed care. And when the clients you serve often have heath problems or disabilities of

their own, the ability to communicate can often be strained. In addition, those who depend upon managed care and interact with it regularly do not have a voice on their behalf. This was one idea mentioned by stakeholders as a potential service to be provided by the Managed Care Ombudsman. The service being given to clients is a neutral voice to advocate for them and to advocate for better services to the client. In addition, the Managed Care Ombudsman would serve as a guide for those entering the healthcare system, and provide assistance when clients change managed care organizations (as this does tend to occur with frequency). There could be an added responsibility as well, having the Managed Care Ombudsman represent the client when a managed care organization stops or declines services. This not only helps to preserve the central theme of advocacy within the Ombudsman program, but can also help when conflicts arise between the client and the managed care organization. This does present a potential conflict of interest, though. An Ombudsman working so closely with a managed care organization while still remaining a neutral entity of the state is a challenge that would need to be carefully orchestrated by the Department on Aging with the help of managed care.

But no matter what the services of the Managed Care Ombudsman are, there is still an issue with *how* the Ombudsman will first interact with clients. Stakeholders referred to this as "the initial point of contact." This means, what is the initial point at which the Managed Care Ombudsman first interacts and/or contacts the client? This is not only a structural challenge for the Ombudsman program, but an outreach challenge as well. Ideas ranged from talking and working with hospital discharge planners, to CAPS meetings, case managers, even churches were recommended. If the scopes of services being provided are not clear to those working in the Ombudsman program, it will make the task of communicating to clients all the more

difficult. And in order to best communicate with clients about the role and services of the Managed Care Ombudsman, we must reach them where they are most accessible and in a position to fully receive the message of the Ombudsman program.

Now let's look to the issues and recommendations for the Homecare Ombudsman. This is an area of special challenge for the Ombudsman program and for the Homecare Ombudsman. This is because not only are defined roles and services needed, but so are answers to very serious legal and ethical issues as well. First, we address possible roles and services that the Homecare Ombudsman could provide, from stakeholder recommendations. Above all, stakeholders wanted to make sure that the Homecare ombudsman would still honor the traditional role of advocacy, and being the voice of the resident when they choose, but also making sure that the client has a safe plan of care when living in a home or community setting. One of the ideas mentioned at a stakeholder meeting in Wheaton Illinois was to have the Homecare Ombudsman deal with clients that are in nursing homes for a short duration of time, then assist them with transitioning back into their homes or into the community. Another idea was to have the Homecare Ombudsman work with those that live at home and receive services for a disability. But as we explore the potential role of the Homecare Ombudsman and the services to be provided, we see the deep legal and ethical challenges that arise when facing the issue of home and community care.

There is a serious concern for safety when working in the field. This is greatly increased when entering a person's private home, because not only are the ombudsman not in a secured facility (as with the Long-Term Care Ombudsman), but in populated urban areas, venturing into

certain neighborhoods could be more dangerous than others. Not only are there issues of safety, but there are serious issues with how to deal with conflicts between the Ombudsman, the client, and the client's family. If there is going to be an Ombudsman working in private homes, there *must* be guidelines and policy in place to not only protect them, but to make sure they can still effectively advocate on behalf of the client. Often, when there is elder abuse, especially financial abuse, the ones perpetrating the abuse are family members. This is easier to deal with when the family member doing the abuse has to go into a facility or nursing home, but when you switch to a home setting, the challenge is exponentially harder to solve. If the client is living with the person abusing them, it is highly unlikely that family member will allow for an Ombudsman to enter their private home. This is why it is critical that when the scope of services being provided is made clear for the Homecare Ombudsman, there must also be clear guidelines set for some of the potential challenges that will be unique to the Homecare Ombudsman's job.

In summary, there is a critical need for a defined set of services being provided and scope of services for both the Homecare Ombudsman and Managed Care Ombudsman. This is needed not only for the creation of policy and guidelines, but for the clarity and understanding of all those involved with the Ombudsman Program. Not only should we consider the needs of both new Ombudsmen in terms of policy, but we should consider potential conflicts that can arise in both fields, and create policy to address this.

Conflicts of Interest

As the program expands and rolls out, there has perhaps been no greater concern than the issue of potential conflicts of interest that arise when expanding into managed and home care. This is because there are so many chances for a conflict of interest to arise. As we will see, the issue is not entirely just conflicts of interest, but making sure that a job or service is not being offered when it is already being provided by someone else. First, let's explore the challenges and recommendations made on behalf of the Managed Care Ombudsman.

This was one area where conflicts of interest seemed to be prone. Managed care organizations had stated previously at stakeholder engagement meetings that a good deal of the information they handle is privileged, and is not something they can just allow anyone access too easily. If we had an Ombudsman working so closely with managed care, there would need to be safeguards in place to stop potential leaks of information, private information on clients or on a facility. Managed care organizations have a very legitimate concern for the safety of their records, and this must be addressed when expanding the Ombudsman program into managed care. In addition, it is *critical* that the Managed Care Ombudsman be kept a neutral, 3rd party entity between the client and the managed care organization. This will not only preserve the role of advocacy but add a layer of trustworthiness, confidence and legal neutrality to the Managed Care Ombudsman position.

Next, we address the areas of concerns for the Homecare Ombudsman. Just like with safety and the definition of services provided, the Homecare Ombudsman will face a unique set of challenges to overcome. One of the main potential for conflicts comes with APS (Adult

Protective Services). This is not something new, and this issue is deeper than just this debate. While the Ombudsman program believes that they owe a duty solely to the client and their wishes, those in Adult Protective Services believe that they owe a duty to the elderly to prevent any and all abuse wherever it may occur. While both sides claim to be right, and can make arguments to that effect, this debate is at the core of the potential conflict of interest by the Homecare Ombudsman. The issue of mandated reporting is one that weighs heavily on this debate, and will indeed do a great deal to shape any potential conflicts of interest in the future. While the Ombudsman program wishes to be a non-mandated reporter, other entities within the state wish to remain mandated; this will breed further conflict within the programs.

But besides mandated reporting, the Homecare Ombudsman might also face conflicts with family members of those they are trying to advocate for. Usually when elderly are living in a home setting, it isn't their home, it's a relative that they live with. This means that not only will the Ombudsman have to deal with the client, but the family of the client, who may or may not want the Ombudsman there. This situation puts not only the Ombudsman in a difficult position, but the Ombudsman office in a difficult position as well. If this program wishes to expand into the home setting, the office must develop a clear policy for when an Ombudsman can and can't enter the home of a private citizen, even if the one they are attempting to visit is not the legal owner of the residence.

There is a potential conflict of interest with legal representation as well. If you have the same lawyer representing multiple departments within the Department on Aging, it is a conflict of interest. This is an area of concern that must be addressed if the expansion plans on moving forward.

In summary, conflicts of interest for the SLTCOP are a tricky field to navigate through. But it can be done. Firstly, one of the ideas to solve this issue would be to have ombudsman declare any potential conflicts of interest when they begin employment. This is a step that is taken by some companies and organizations to help avoid any future conflicts. In addition, the presence of clear services provided and roles of the Homecare and Managed Care Ombudsman will help to alleviate and clear up any potential conflicts of interest that can arise. Once it is clear what each new ombudsman will be doing, it will be much easier to predict conflicts. The issue with Adult Protective Services must be dealt with as well. This too is not hard, but requires open and honest communication throughout the expansion process to ensure that both sides are providing services without conflicting with each other. There must also be clear policy that guides the Managed and Homecare Ombudsman that pertains to their rights of access to the client and their records. No matter what the Homecare or Managed Care Ombudsman services are, though, the issue with legal representation between departments is a critical issue and must be addressed.

Staffing

Staffing is an issue that was raised several times during the Stakeholder Engagement process. The issue of staffing brings to light the geographical and social differences facing the expansion of the Long-Term Care Ombudsman program. In Chicago in particular, it was made clear that there is an issue with the amount of staff that are available to the LTCOP. Because of the vast number of nursing homes, beds and residents that are being served in this population area, it makes the job of the Ombudsman all the more challenging. As we expand the program into the home, community and managed care setting, this need for staffing will become paramount, making this one of the biggest structural recommendations for the Long-Term Care Ombudsman Program. But this message should not be confused and misinterpreted; the need for staffing is one that should be looked at and assessed by region, not as a whole.

In Chicago, the issue is simple: they need more staff to effectively advocate for residents in the way the LTCOP has traditionally done. This issue becomes different downstate and in other areas outside of the city of Chicago. In other parts of Illinois, the need for more staff was expressed, but there was also a big concern with adding too many people. This is because as it exists now, the Ombudsman program works with those who are elderly and possibly facing mental disabilities; by adding too much new staff or new people to contact/work through, there was a concern expressed that the system may become bogged down. Thus, the need for staffing is beyond just hiring people to fill any needed gaps, but hiring effective staff that do not create a bureaucracy for clients to have to sift through. Communication is already a tough challenge to tackle as it is, and we must make sure that if new staff is hired, it does not create

any additional (or minimal) lines of communication clients have to go through to receive services.

The threat of a potential bureaucracy should not stop new staff from being hired, though. Addressing this issue on a regional and local level will greatly increase the effectiveness of the Ombudsman program, as well as boost the confidence of the staff already in place. One of the ideas mentioned for the roll-out of this expansion is to use pilot programs in select counties or regions of the state. If this choice is made (using a pilot program) then the need for staffing both inside and out of the city of Chicago could be tested to see exactly where and how many staffers are needed. The idea of using a pilot program to test the need for more employment was mentioned at a stakeholder engagement meeting, and the idea did receive some support.

The issue of staffing also ties into the issue of conflicts of interest. That is, when hiring more staff, the SLTCOP must make sure that the job duties of the new staff are not already being provided. This too was mentioned as a concern by stakeholders, and is a re-occurring concern mentioned at meetings. The issue here is larger than just filling gaps, it's making sure we keep a proper level of staff needed to run the basic functions of the office while maintaining a streamlined process for advocating, handling complaints and any other issues raised by residents.

In summary, the issue of staffing exposes a larger rift within the Ombudsman program. Because Illinois is a state with such a varied sociological and geographical spread, the needs in one area will not necessarily match the needs of another area within the state. Therefore, our

solution(s) to the issue(s) presented by staffing should not be binding and state-wide, but rather they should be regionalized and set to address a specific need in a specific area of the state. It is highly recommended that additional staff be given in the Chicago-land area, but other areas of the state should be assessed individually to see their specific staffing needs.

Institutional Recommendations

Training

If there was one concern expressed more than anything else, it was the need for training. This one topic alone dominated the stakeholder engagement process. Institutionally, this is the largest and most critical issue to be dealt with. This is because of the far reaching implications of the training in the new expanded Ombudsman Program. Training is a large and complicated area to cover; we begin with the system as a whole.

Currently, the training for Ombudsman covers the scope of the services they will provide, as well as touching on information pertaining to SHIP, BEAM, Managed Care and other aspects of the long-term care program. This hints at the first recommendation to be made for training: the training going forward m*ust* continue to be multi-disciplinary. This is because when you take this approach, you don't just learn your role, but how your role impacts and plays into the system at large. This is a critical factor to distinguish when training employees in the expansion. By learning this way, we can teach those involved more than what they do, but what others in the system do. This is known as cross-training. We *must* make sure to educate our staff about the different aspects of the LTC system, and our healthcare system as a whole, not just the Ombudsman program. Many regional and local stakeholders expressed dismay that they were not fully educated in areas such as managed care, insurance, AAAs, MMAI and other programs outside the Ombudsman program. Meanwhile, stakeholders outside the Ombudsman program expressed dismay in not fully knowing the LTCOP. This can easily be solved by having an all-inclusive form of training that makes sure to include representatives from managed care, homecare, insurance, MMAI, AAAs and all other stakeholders who play a role in working with

the Department on Aging. Cross training and multi-disciplinary is *critical* to the survival of this program and to keeping our employees and stakeholders fully informed not only about their job duties and responsibilities, but others' as well.

While this may sound like a mammoth challenge, it is rather simple. Ombudsmen and other staff are required to complete yearly hours of continuing education each year. This presents a perfect opportunity to educate on managed care, homecare and other programs that are used on a daily basis. But more than Ombudsman or Department of Aging staff, nursing home administrators and staff, providers, CCUs, all should be trained in coordination with staff. This ensures that everyone is "on the same page" and understands the role of the Ombudsman and other Department on Aging staff.

This training goes both ways as well. Not only should stakeholders learn about the Department on Aging and our programs, services and processes, but staff from the Department on Aging should be learning the fine details of MMAI, managed care, SHIP and other large, vital programs in the Illinois Healthcare system. Ombudsmen and their staff should learn the inner-workings of these organizations so as best to know how to solve issues that come up with these institutions regularly, and who to contact when these issues do arise.

But more than understanding roles and responsibilities, these trainings will provide the breeding ground for connections within our state-wide health network. By bringing together managed care organizations, providers, CCUs, case managers, nursing home administrators and staff and all other stakeholders in addition to Department on Aging staff, we will be giving each other the opportunity to create much needed contacts within our healthcare system. This is not

a new concept or phenomenon; this occurs all the time during conferences, intra-department meetings and other professional events. These contacts are already in high demand in many places all over Illinois, and many stakeholders expressed a serious interest in working closer with managed care, providers and other stakeholders to streamline issues faced in the field. By using cross training, we will be able to not only give quality training, but have the added benefit of creating vital new connections in our field. But, like other recommendations made in this report, the training should be regionalized. This is because often the resources needed by regional and local ombudsmen can be found within the same region they work in; they just need to make the connections to providers, managed care organizations and other stakeholders. In addition, regionalizing the training will give those working in those regions better access to local resources to work with in the field. Most critically, these trainings *need* to be person-to-person connections. Training should not be strictly limited to online services. If this cross training and cross referencing is going to work, there must be an in-person connection made between those involved. Online training allows the possibility of reduced attention to the details being presented; details which can often be hard to follow because of their complicated nature. By making the trainings in-person and open to all stakeholders, you bring more knowledge and resources to the table all at once, giving staff and stakeholders more to training with and communicate to each other with.

There was an interesting response when stakeholders were asked what training the Homecare Ombudsman and Managed Care Ombudsman should receive. The managed Care Ombudsman should, of course, be highly trained and well versed in the managed care system, organizations and processes. In addition, a close attention to conflicts of interest should be paid

when training the Managed Care Ombudsman, due to their close proximity to sensitive information. The Homecare Ombudsman was a more complicated issue. Because the Ombudsman will be entering private residences, the legal ramifications for the state and the employee are greatly altered. We must train the Homecare Ombudsman thoroughly in the laws regarding entering/exiting a private residence, privacy and rights to access laws, self-defense, and other forms of education one would need when entering and exiting a private residence on a daily basis.

Besides the critical need for cross-training and training for the new Ombudsmen, there is a need to have specialized individuals within the Department on Aging, specifically the Long-term Care Ombudsman Program. At the meetings, stakeholders expressed a wish to have two highly trained employees, one fully versed and trained in the inner-workings and fine details of managed care, and other specialized in Homecare. These positions would not just be for general knowledge, either. It was expressed by stakeholders that they wished these positions would be more resourceful, offering contacts, tips, guidance/advice and policy for dealing with managed care and homecare providers. These positions would serve as “know-all’s,” or “go-to people” if you will. Someone who anyone within the Department on Aging (or outside the Department on Aging) could go to if they needed information pertaining to managed care or homecare, as well as on our own managed care or homecare services. The idea here being that there would be one person you could call if you ever needed help with homecare services or organizations, and having another person who specialized solely in managed care and managed care organizations. But again, as mentioned previously in this report, there are concerns with duplicating services that are already provided, as well as funding. There is only so much money

to hire and train new staff. If there are already people in the LTCOP or another state agency that can serve this purpose, that information should be shared with stakeholders. Or, more simply, if this position does not already exist, fold these responsibilities in with the Managed Care and Home Care Ombudsman.

A third concern raised with training was the need to have *continual* training. Bringing everyone together and training them is a good start, but this process will be on-going. As our program expands out over this year and years to come, other entities within the state healthcare system react and adjust accordingly; there will be new policy and new rules to work within. This is something that must be seriously considered and incorporated into training. As new changes and policy arise, training should reflect these changes. The Illinois Healthcare system is a vast complex, with many moving parts. And while it is unrealistic to think we can train every single person in every single aspect of this complex, there should be a continual effort made to keep training and re-training those involved in the system on the updated rules and procedures that guide their jobs as well as the jobs of those they interact with.

But now we must address *when* this training should begin. It would be a great waste of time and effort (and common sense) to try and organize a training effort such as this without having the details of the new Ombudsmen worked out; on a legal, policy and administrative level. This is why training is such a critical institutional issue to this expansion. After the Homecare and Managed Care Ombudsman have been firmly backed by policy within the department and law, training should inform any and all stakeholders of these changes. While the training should begin *after* the policy surrounding the expansion has been fully

implemented and in place, the training should also come *before* the expansion begins to roll out fully across the state. It would be equally unwise to start expanding without any training as it would to start training without any policy or legal details. Once the Department on Aging has established its policy and legal assertion of the expansion, training should commence, by region, and have the roll out follow immediately.

In summary, the need for training was one expressed by far more than just stakeholders. There is a serious need for further training as the program rolls out. This training should be inner-disciplinary, and should cross-train stakeholders on as many aspects of the Illinois Healthcare system as possible. Training should be all-inclusive, and welcome any and all stakeholders so as to gather as much knowledge and experience as possible. The process of training should be in-person, and designed to build connections within the Department on Aging as well as with stakeholders outside the department. Training should also be continual; as new policy, laws and administrative decisions are created, this information should be shared with any and all stakeholders.

Communication

This section should not be taken as an "issue" but rather a recommendation to guide the institutional change that will occur from this expansion. In every single stakeholder meeting, there was a desire expressed that the engagement process be continual. By law we have engaged with those that work in this field in 6 geographically located meetings (one more was planned in Oak Park but was canceled due to severe winter weather, as noted earlier in this report) and the feedback has been tremendous. And above all, there was a desire to continue the process of meeting and discussing ways to improve the expansion as it rolls out. This can be seen in the recommendations made by stakeholders to have continual training as well. Again this should not be read to mean that the Department on Aging has not already made attempts to be communicative with stakeholders, but rather that this communication *cannot* disappear as the rollout goes on. There was a continual worry that once the engagement process was over, administration with the Department on Aging would "disappear"; this is something that cannot happen.

Stakeholders were responsive to the engagement process, and expressed a desire to keep the engagement process continuing. Therefore, a recommendation would be to keep the process of retaining feedback from stakeholders open as the process of rolling out the expansion occurs. As policy and law is established to bolster the program, there should be continual feedback and engagement with stakeholders to gauge the potential impact and effects of the new policy and/or law. Since many of the stakeholders that responded to our engagement process were local and regional staff, they will be the ones to best establish the

ground-level impact of the policies we implement. Continuing a strong line of communication will be essential to the success of this expansion.

This includes opening more dialogs with others in the Department on Aging; creating more lines of communication between the SLTCOP and APS (Adult Protective services). By doing this, we can help to alleviate potential conflicts of interest before they appear in policy or in practice in the field. Strengthening the communication between different programs and offices within the Department on Aging will give us a focused and concise message to deliver when communicating down to those in the field and those in other agencies or organizations. Many stakeholders expressed a concern that without more clear communication, there would be conflicts between the SLTCOP and APS; but these conflicts can easily be avoided with good dialog during the creation of policy and legislation moving forward.

This also goes past inner-office communication; the Department on Aging should reinforce lines of communication with other departments in the Illinois healthcare system. This means strengthening ties with HFS, HHS and any other government or private agency that we encounter on a regular basis. While we reach out to expand networking and communication in the Illinois healthcare field, we must be sure to refrain from any conflicts of interest in collaborating.

As for actual ways to keep communication lines open, stakeholder suggested a simple solution: hold quarterly stakeholder engagement meetings either in person or via teleconference (since going to so many geographical locations could be inconvenient or undoable at times during the year). This ensures that as the program expands, we are sure to

keep those in the field in dialog with policy and law makers within the department. This meeting (or meetings) should be all inclusive, just as the last engagement process was. The 6 engagement meetings yielded stakeholders ranging from nursing home administrators and staff, to regional and local Ombudsmen, to Illinois representatives and their staffs as well. By taking in responses from such a varied and educated background, we have been able to identify many potential problems before they occur and fix them. This is something that should be maintained, and be included in the policy and legislative considerations moving forward.

In summary, the Department on Aging has gone to great lengths to gather feedback and ideas from those most involved and most informed on the ramifications of the expansion for ideas and suggestions on moving forward. There should be a continued and focused effort to collect feedback as the expansion into home and managed care continues. This will help us with potential conflicts of interest, both inside and outside of the Department on Aging. When changes in policy and law are created and instituted, the Department on Aging should go to great lengths to make sure that stakeholders are not only aware of the change, but are given time to give feedback on the possible repercussions of the new changes.

Publicizing the Expansion

This was an area that received lots of good feedback from Stakeholders. The issue of publicizing the expansion is a unique one for the Department on Aging, but is critical to ensuring the success of the expansion. This is one of the more prominent institutional recommendations that can be made. This step should also be one of the final steps as well, due to the fact that there will need to be a clear and concise message delivered to stakeholders, residents of nursing homes and family members of clients on the services and responsibilities of the Home and Managed Care Ombudsman. This issue is two-sided; the LCTOP and the Department on Aging must publicize the expansion to both clients and stakeholders, each requiring a different method to be successful.

No matter who we are addressing though, the central issue to reaching people is finding an effective "point of contact." The "point of contact" is a term that refers to the first time a client encounters the Long-Term Care system. No matter what waiver they have for services, or what type of care they will receive, every client has an initial point of contact with the system. The importance of this encounter cannot be overstated. Reaching clients at this time is the most critical for delivering the message of the SLTCOP. But this is where the ability to market the expansion can be tailored. This can be done a number of ways. Firstly, for home and managed care, there are discharge planners at hospitals and nursing homes that can be utilized to give out information about our programs and services depending on what program the client is planning on entering. Since these people will be familiar with the client's case and background, they can be a good source to deliver the contact information and scope of the

SLTCOP. In addition, case coordinators and social workers can be utilized if a person is planning on entering the Homecare program. Both of these have access to the client and their needs, and can give out the information on the Ombudsman program. Homecare can also benefit by using community resources, such as churches and town hall meetings. For managed care, those entering this field can be first contacted via the Enrollees Handbook, a guide given out to new clients of managed care. In addition, case managers with managed care organizations can also be utilized to deliver the message due to their knowledge and close contact with the client. But what about the clients themselves? How do we *actually* address them?

It was mentioned at stakeholder meetings that when addressing an elderly client about the expansion, there may be issues with effective communication. Elderly clients may not fully understand the new roles of the Homecare Ombudsman and Managed Care Ombudsman. In addition, there may be issues with mental health or lingual problems. Some elderly clients simply cannot communicate. Others may be illiterate. We must be able to reach clients who use alternate communication skills, as these are the most critical of the clients we serve. If we are going to reach these clients, we must make sure to develop a line of communication that is not overly reliant on legal and technical explanations. It is very possible that a client will not understand the expansion if explained in a purely legal or technical way. The Department on Aging must make sure that when addressing clients about the expansion, they do so in a way that is conducive to the ability of the client to understand and retain the information. This can be done by creating pamphlets that are language neutral or use minimal language to convey the message. This will help to communicate to clients who are not lingual. There should also be an effort made to reach those that do not speak English. The publication of materials in

Spanish, Polish, Korean, Mandarin (Chinese), Arabic and Urdu in addition to English should be utilized, as these languages are very prominent in Chicago and other large urban areas.

In addition to reaching out to clients on an individual level, the Department on Aging should take steps to broadly publicize the expansion to the public in mass. This can be done a number of ways, most effectively by region. In Chicago and the areas up north, the use of public access television (PBS) or other local networks can be very effective, as the population that views these stations tends to be older. In addition, use of local newspapers and local support from the city and local organizations will be most critical to publicizing the expansion.

In rural areas, it is again necessary to look to local and regional support methods for publicizing. For example, the Belleville News Democrat is a long established newspaper in eastern and central Illinois that enjoys over two hundred thousand regular readers. This is just one of many local resources mentioned by stakeholders that could be used to get our message out to the local populous in regions that are less densely populated than others. In addition to local newspapers, rural areas could be accessed via case coordinators and case managers, who will have a good knowledge of local resources and organizations, as well as the clients.

Using the internet can certainly work, but again we must remember our target audience. If we are trying to reach managed care organizations, insurance companies, or stakeholders that work within the system, the use of internet institutions like Facebook, LinkedIn, YouTube or government websites can play an effective role. But if it is the elder clients we are trying to reach, then this plan may fall short of achieving a desired level of outreach. Like the other forms of publicizing, it is critical we understand our target audience

and triage methods of outreach based on geographic and sociological conditions within a given region. To try and come up with a broad, state-wide plan to solve the issue of publicizing is not recommended.

In summary, the publicizing of the expansion is a critical step, but one that should be taken after all details about the program have been fully disclosed and finalized. This is because we must have a clear and concise message to deliver to clients, their families and stakeholders about the reason for the expansion, new services provided and how to contact the Ombudsman Program. This publicizing will rely heavily on regional support methods. By localizing the efforts to market the expansion, we can not only build upon existing community resources, but effectively target our audience. But at its core, the issue of publicizing the expansion is one of communication. We must have a very easy and communicable message to deliver, then find the best ways of delivering it regionally. By targeting both the clients and those that serve them, we can ensure that both get the message. And by using tools such as local access television, public broadcasting, local newspapers, churches, town halls and public forums, as well as case coordinators, discharge planners, social works and case managers, we can ensure that our message is received locally by those in the community. It is critical that we identify “points of contact” as well. A clear, unified and communicable message is one that will have the best chance at being received, a task that should be a top priority for the Department on Aging when other details on the expansion are complete.

Resources

Data Collection

Data collection is one of the trickier and more sensitive aspects of the expansion, and one of the more debatable resource-based recommendations. This was an area that saw a wide array of responses from stakeholders on the importance of data collection, the use of the data collected, and the repercussions of collecting data. Stakeholders were asked about their thoughts on collecting data that could be retained for use anytime, 24/7. Firstly, when asked, many stakeholders questioned the need for additional data to be collected at all. The office of the State Ombudsman already collects data via services like Ombudsmanager, monthly reports, figures from nursing homes and other state departments. Currently, the data collected by the department is basic data, with Ombudsman being able to retain medical records from a facility if needed and approved by the resident. Still, as the program expands the need for increased data on nursing homes may be necessary. This is especially true in urban areas that have a greater number of nursing homes, and thus a greater number of discharges per day, residents to see, and reports to compile all to be looked after on a regular basis. One stakeholder wisely asked, "We need to ask ourselves what we consider a successful outcome of collecting data." This comment is paramount to the issue at stake here. Not only do we need to clarify exactly what data we wish to collect, but the means of collecting it and what we do once we retain it are critical factors.

First, the Managed Care Ombudsman. This is a hard issue to solve, in part because it depends largely on the Managed Care organization. There are several in Illinois, spread over different geographical regions. As mentioned previously in this report, the managed care organizations will not lightly give up the records they hold on clients. This is a legal protection

afforded clients. If the client signs over the right to access their records, however, this can be relieved. But still, getting additional records from a managed care organization is a tough job, and one they may not support. This could cause conflicts in the future, and clear policy should be developed to address the Managed Care Ombudsman and their rights to access data and records on behalf of the client.

For the Homecare Ombudsman, the issue changes; in Chicago, it was mentioned that the type of data collected could be changed to suit the needs of a dense urban environment. Because some of the neighborhoods are not as welcoming as others, it was mentioned at the Chicago stakeholder meeting that if data is going to be collected, those in large urban areas have access to the records for previous visits, any previous issues with the resident, both in terms of complaints filed on behalf of the resident or issues with the resident themselves (if the resident is violent, for example). But there is also a concern with the resident's family members, and if there have been problems there in the past as well. Some of the data recommended is taken included records on previous financial abuse of the client, mental health data (status) of the client, any previous crimes committed by the client, status as a sex offender, ect. Some of this data (mental health data, previous abuses, family structure) can be provided by facilities. But other records may be more challenging to obtain. These recommendations come because of a concern expressed in Chicago that with loosening gun laws, and such a large population of residents to serve over such a broad geographic area, the concern for safety is paramount. This issue is central to the Homecare Ombudsman's role in Chicago or other large urban areas. Thus, in these large urban areas, the issue of data collection is one that turns toward the safety

of the Ombudsman more than empirical data on nursing homes and residents (though that too was expressed).

There was a more interesting response from stakeholders when asked about 24/7 access to data and records. In urban areas especially, it was mentioned that by collecting a greater and greater amount of data, it may twist the image of the Ombudsman program. The Ombudsman program is one that is centered on the idea of person-to-person connection, and requires a close relationship with the client to be truly effective. By becoming more proactive in our efforts to collect data, we risk presenting ourselves as something more than an advocate. We must remember, we work in the bubbler of this field, but those that enter the Ombudsman program or enter a nursing home are usually not completely knowledgeable about the services we provide. To an elderly resident and their family, the collection of data may appear very different than it does to us in the field. By telling people that we will have 24/7 access to records we risk giving them the image that we are akin to law enforcement or some sort of emergency service that can respond 24/7. This is not the role of the Ombudsman program. We are advocates. Pretend for a moment you are not reading this report; and say the words “data collection” to yourself. What do you think of? Odds are, if you’re most Americans, when you hear “data collection” you think of all the recent debate about the revelations of the NSA, Edward Snowden and current and previous presidential administrations’ spying programs. In the last five to ten years, the concept of “data collection” has skewed to take a very negative connotation, and has come to represent the over-reaching of governmental entities. It’s highly likely that people will make undesired assumptions about our collecting data if they hear about it. This is a *serious* issue to the Ombudsman Program because again, our entire process depends

upon the trust and person-to-person contact. In collecting data, we must retain our role as an advocate and make sure that we avoid any conflicts of interest and respect the records we are seeking to collect. But this issue speaks to a larger concern: the concern that the Ombudsman program is expanding beyond its scope and traditional purpose of advocacy. Collection of data has a role to play in this process, but just how much should be carefully reviewed for unintended consequences and perceptions.

There is still one issue left to clarify, however. Once we have decided what data we are to collect, and how we will collect it for both new Ombudsmen, the issue turns to how we will use the data. You can collect as much information as you want, but if you have no means of delivering or accessing it, the information is useless. While the LTCOP already has Ombudsmanager and other means of delivering data, there should be a plan in place that allows for more regionalized data to be accessed by the Ombudsman. The more easily they can access records, the more we can streamline their job.

In summary, the issue of data collection brings to the surface other issues. Like other topics in this report, the issue is much deeper than finding out what data we need. A regionalized approach is better here, as the methods for collecting data are not necessarily the same over the whole state. In Chicago and other urban areas, there is a need for not just the basic records afforded to the LTCOP, but also records that relate to the safety concerns for the Ombudsman and their staff. This was a central concern for the Homecare Ombudsmen; however, we must do so in a way that maintains the sanctity of our advocacy role. But for the Managed Care Ombudsman, a close line of communication and cooperation with managed care

is necessary to make sure there are no conflicts when trying to access records. The SLTCOP should develop clear policy to guide the Home and Managed Care Ombudsman for obtaining data and records from clients and facilities. In addition, the SLTCOP needs to assess the use of the data collected; making sure it is readily available to the regional and local Ombudsman for use when they need it. All of these are subject to funding, though. Much like other issues in this report, the collection of data is, above all, subject to tight budgeting. This forces us to further scrutinize just how much of a role we wish data collection and retention to play in the expansion of the Ombudsman Program.

Funding

Nothing in this report can escape this reality. Funding is the critical element that will determine how far this program can go. The Department on Aging has been aggressive in acquiring funds for the expansion, creating grants and proposals to open up new forms of income from both the state and federal government. Still, there persists a consistent worry among stakeholders that there will not be enough funding to support the expansion.

This worry was not that the program would not be funded at all, but rather that the quality of services would decline substantially under the weight of new responsibilities added by the expansion and a lack of funding to make up the difference. This strikes at the heart of the issue that underlies funding: it impacts every aspect of this expansion. Funding is needed for data collection, training, publicity (for the expansion) and most critically, staffing. It's no secret that funding is the most critical element on this equation. But here, like in many other areas of this report, the need for funding should be regionalized. The need for an increase in funds is far more critical in some areas than others. Therefore, it is recommended that each region be assessed individually for its own funding needs. In Chicago, there is a serious need for funding to provide the staff needed for the expansion. In other areas of the state, this need may parallel, not be as great or may not exist at all; but the point remains the same, funding should be looked at on an individual basis by region. This allows the department and the LTCOP to fully analyze how each region can expand into managed and homecare in the best way that fits the regions needs. It also gives the department and the LTCOP the opportunity to ensure that services are not being duplicated, a factor that could easily cost the department money

unnecessarily. The issue of funding is one that forces the expansion to occur in the most efficient manner possible.

Funding for staffing is especially critical, as staffing is one of the most important aspects of the expansion. Training should also be a funding priority. Once it has been established what kinds of training should be given and just how it will be done has been established, there should be funding set aside to fully cover the costs of properly training stakeholders in the expansion.

Publicizing the expansion should not be a massive funding priority. This is because the message we are trying to get out isn’t for the entire world (per se); we are not advertising a movie or product. This expansion has an audience that is made of healthcare professionals, stakeholders in the Ombudsman program, the clients we serve and their families. This message should cater to the best way to reach out to these audiences, in a regionalized method. Much of this publicizing is expanding lines of communication that already exist. This is about opening up our communication to include other areas of the Department on Aging as well as professionals from other agencies and organizations within the state. And with a regionalized approach, the ways of reaching out to publicize the expansion can be uniquely tailored to each region’s demands.

Other areas of this report such as defining roles and services to be provided, publicizing the expansion and expanding communication are all less focused on funding sources as much as they are focused on networking and dialog. Part of this expansion will require a good deal of financial investment by both the state and federal government. But outside of funding, we must make sure we are creating a dialog with other areas of the Illinois healthcare system to make

sure the investments we are making are not only going to good use, but can produce detailed and traceable results that can show the progress of the expansion (which in turn will help provide more funds).

As noted earlier, though, funding *is* being addressed by the LTCOP and by the Department on Aging. The approval of an MMAI grant in late 2012 has allowed funds to be invested into the program over 3 years. This was a critical grant proposal for the expansion, and the funds will go to great use as the expansion comes into full swing. Still, the process of creating proposals for new funds is on-going. This process should continue and both the Department on Aging and the LTCOP should work together in securing funds for this expansion.

In summary, the Department on Aging has made a substantial effort to secure funds in support of the expansion into homecare and managed care. This effort is on-going, and will continue as the program expands. Besides seeking grants and proposals from the state and federal governments, the Department on Aging and the LCTOP should ensure that as they expand, there is no duplication of services that would otherwise cost unnecessary money. This, in addition to regionalizing the need for staffing, training and publicizing can also help to save money. In addition, pressing members of the legislature for additional funds is also being employed, but this too takes time. While the need for funds is critical, the program is able to move forward with the expansion due to the tireless efforts already made, and still being made.

Conclusion

Over a month and a half time-span, the STLO office held 6 stakeholder meetings, with one in Oak Park being canceled due to extreme weather. These meetings hosted those that are truly the foundation of this program: those that work every day in the field with nursing homes and clients. Because they will be the first to encounter any problems faced with this expansion, it was their feedback that was so critical to this process.

The recommendations we gather touched on every point in this expansion. Firstly, there was a serious concern for the role and safety of the Homecare Ombudsman. Because the position requires the entering and exiting of a person's private residence on a daily basis, and will require close contact with family members and records, there are critical ethical, legal, and policy questions that need to be addressed. The Managed Care Ombudsman faced concerns over not only the complicated nature of the position, but concerns over conflicts of interest and services to be provided. Both of these positions were greeted with excitement, but also concern.

While these recommendations may appear to be many and far reaching, addressing them is actually quite simple. Once roles and services are defined for both the Homecare and Managed Care Ombudsman, it will be much easier to detect and avoid future conflicts of interest. In addition, training and staffing needs will be able to be addressed, and disseminated throughout the state. By this point, communication to stakeholders should be greatly increased because of the influx of policy and administrative details on the two new Ombudsmen.

Addressing these issues will not only resolve the issue at hand, but help to solve other issues listed in this report.

It is no secret or surprise that there are many challenges for this office and for the Department on Aging at large to overcome as we expand our LTC program into home and managed care. There are issues with staffing, funding, potential conflicts of interest and training. But these challenges can be overcome and set a standard not just in Illinois, but nation-wide for quality long-term care, homecare and managed care. If we can not only address but fix the issues that face this expansion, we instill a greater discipline into our programs and services, as well as give confidence to those working in the field and on the ground with this expansion. If stakeholders are not fully understanding and comfortable with the expansion, there will be little chances of success. We must make sure that the Department on Aging, the Long-Term Care Ombudsman Program and any other stakeholders are all in unison with the legal, policy and administrative guidelines for the new Ombudsman and for the new services being provided. A clear and concise message, in addition to quality training, communication and staffing, coupled with solid legal and policy framework and backed by funding will guarantee the success of this program and the expansion into home and managed care.

Quick Reference to Summary of Recommendations

Definition of Scope and Services

- Clear definition of services provided by both the Home and Managed Care Ombudsman are critical. In addition to these services, an explanation of the scope of the office on a legal and policy front is needed to help identify any future conflicts of interest.

Conflicts of Interest

- Having Ombudsman and staff formally declare any potential conflicts of interest upon hiring

- Meeting regularly with Adult Protective Services and other programs within the Department on Aging to ensure that conflicts are avoided as the program expands

- Addressing the legal conflict of interest by having multiple programs within the department sharing the same legal counsel.

Staffing

- Adding additional staff to the Chicago-land region to ensure that quality services are provided before, during and after the expansion of the program

- Assessing the need for further staffing on a regional basis to assess each area's specific staffing needs

Training

- Training should be all inclusive, and should be in-person (not online!) and designed not only to train on policy and legality, but should draw upon the combined knowledge of those present to build connections within the Illinois Healthcare system

- Training should be continual, and should inform stakeholders on the newest and most recent updates on policy, law and administrative decisions.

- Training should be established by region to draw out and include local experts and organizations

Communication

- Continue to meet and collect feedback from stakeholders on a regular (annually, bi-annually or quarterly) basis

- Let stakeholders give feedback *before* new major policy is implemented

Publicizing the Expansion

- Regionalize the approach to publicizing to find the best forms of communication to our target audience within a given region

- Identify key "points of contact" with managed and home care participants

- Utilize local resources to best reach stakeholders, clients and the family of clients.

Data Collection

- Regionalize the *types* of data needed to be collected. Assess what regions of the state need what types of data collection

- *Carefully* choose which pieces of data and information to collect and retain

Funding

- Review each region of the LTC program individually to clearly decide where funding is most critically needed

- Continue to create grant proposals for additional funding

- Monitor any and all gains and benchmarks so they can be reported, in the hopes of receiving additional funding.