FINAL REPORT

A PROJECT TO ASSESS WHAT IS NEEDED TO PREPARE OLDER AMERICANS ACT LEGAL SERVICES PROVIDERS TO REPRESENT OLDER CLIENTS WITH MENTAL ILLNESS



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- Laurie Hallmark, JD, Special Project Director, Texas RioGrande Legal Aid, San Antonio, TX
- Marshall Kapp, JD, MPH, Professor Emeritus, Florida State University, Tallahassee, FL
- Victor Molinari, PhD, Professor, School of Aging Studies, Behavioral and Community Sciences, University of South Florida, Tampa, FL
- Ann Renaud, JD, Ramp, Renaud & Hlavenka, LLC, East Brunswick, NJ

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PART ONE. INTRODUCTION/ BACKGROUND ON THE PROJECT

I. Project Purpose: A Critical First Step

The Georgia Legal Assistance Developer (GA-LAD) and The Center for Social Gerontology (TCSG)¹, jointly requested funding to take a critical first step toward achieving a workforce of Older Americans Act (OAA) legal providers (and others providing civil legal services) that is prepared and equipped to provide high quality representation to elderly clients with mental illness. (See Appendix 1 [pg.60] for a one-page Summary of the Project.)

The goal of this project is to begin to lay a foundation for what is needed to enhance awareness and preparation of our OAA IIIB providers (and others in the civil legal services workforce) to provide representation to older persons with mental illness in cases that are substantively about something other than the client's mental illness. We are inadequately preparing our legal providers if we fail to take every opportunity to assure that guidance is provided to enable them to provide representation to these clients.

One of the most important things we have learned in the elder law field is the importance of gaining the trust of older clients, which is sometimes difficult. It is common knowledge that mental illness continues to carry a stigma.² That stigma potentially prevents an older person from seeking needed legal assistance or from readily volunteering information about mental illness for fear that an attorney may consider mental illness a barrier to legal representation. Thus, a part of our goal is to ensure that does not happen by recognizing what is needed to better represent and help gain the trust of older clients with mental illness.

As a foundation for supporting the work of developers and OAA IIIB providers, we searched the OAA for connections between what this project seeks to accomplish and what the Act currently requires of legal services providers. Even though legal services are a priority within the OAA, the provision of legal services to older persons with mental illness is not expressly mentioned. However, we do find that this vulnerable population by definition is included within the fabric of the language and

¹ Investigators: Natalie Thomas, Legal Assistance Developer - GA; Penelope Hommel, Director and Laurie Lisi, Consulting Attorney, TCSG

² Parcesepe, Angela M. Cabassa, Leopoldo J; "Public Stigma of Mental Illness in the United States: A Systematic Literature Review", Adm Policy Ment Health. 2013 Sep; 40(5): Retrieved March 1, 2019 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3835659/

definitions of the Act.³ This was enough to satisfy us that our goals would be in keeping with the overall spirit and mission of the OAA as intended for OAA IIIB legal services providers as they strive to serve some of the most vulnerable older Americans.

II. Four Specific Objectives

In order to achieve our Goal, we set the following four specific Objectives:

- ascertain (through a survey) the baseline awareness/preparedness of OAA IIIB legal providers to work with older clients with mental illness by asking them to identify existing training and research resources, as well as resources they need but are not available;
- gather input from experts in geriatric mental health/mental illness and lawyers specializing in serving clients with mental illness (key informants) on 1) resources/research/writings they believe would likely benefit IIIB providers; 2) things they would recommend as best practices; and 3) challenges in working with older clients with mental illness;
- review available resources and analyze/synthesize the input obtained from the experts, extrapolating "best practices" and challenges; and
- develop recommendations for necessary "next steps."

We are currently relatively well equipped to meet the legal needs of elderly clients with dementia and or physical disabilities but very much less equipped to serve those with mental disabilities. Regrettably, if IIIB legal providers are not sufficiently aware and prepared to work with clients with mental illness, they may inadvertently be less compassionate and more likely to summarily dismiss those who present with signs or symptoms of mental illness.

III. Overall Approach to the Project

To identify how best to move forward to prepare legal services programs to handle the representation of elders with mental illness, the project was to identify existing resources, as well as gaps in these resources. The overall approach to the project was two-fold:

³ 42 U.S.C. § 3002(13) - the term "disability" means (except when such term is used in the phrase "severe disability", "developmental disabilities", "physical or mental disability", "physical and mental disabilities", or "physical disabilities") a disability attributable to mental or physical impairment, or a combination of mental and physical impairments, that results in substantial functional limitations in 1 or more of the following areas of major life activity: (A) self-care, (B) receptive and expressive language, (C) learning, (D) mobility, (E) self-direction, (F) capacity for independent living, (G) economic self-sufficiency, (H) cognitive functioning, and (I) emotional adjustment.

- A. To seek advice/input of key experts in geriatric mental health and legal representation of clients with mental illness to gain their perspective on what legal providers need to know and understand to best serve this population; and
- B. To survey OAA IIIB legal services providers regarding their preparedness to serve this population.

Then, by analyzing the information gleaned from the experts and from our survey, we created written recommendations for next steps for developing needed training and resource support materials on this critically important, but under-explored topic.

IV. Impetus for the Project & Preliminary Research

The impetus for this project was loosely related to a need expressed by one of Georgia's IIIB legal services providers for training on representing older clients with mental illness. The need expressed by the provider specifically excluded the need for training on representing clients with Alzheimer's disease and related dementias, as this has been addressed.

In response, the Georgia developer conducted a series of searches for currently available resources that would meet the identified need and for agencies believed to be knowledgeable about this subject area. Agencies were contacted and asked about the existence of relevant training and resources and some of their responses, which appear below, convinced us that we needed to pursue this subject further.⁴

- a) "Thanks again for bringing up the need for legal training on this topic. We frequently receive requests for this, and it is an area where I'm not finding additional resources. I hope we will create one in next year's National Legal Training Curriculum."
- b) "Wow, as always you have zeroed in on an important and complex topic that obviously needs more work. As always, you have already made a hefty start in looking at all of the aspects of what is needed -- in this case, for training of lawyers representing clients with mental illness."
- c) "I'm not aware of any training materials specifically covering the matters you describe. I've sent some inquiries to colleagues to see if anyone else knows of such trainings. If I learn something that may be of help to you, I will let you know."

 ⁴ a) Fay Gordon <fgordon@justiceinaging.org> (Sent: Friday, July 13, 2018 11:29 AM); b) Wood, Erica
 <Erica.Wood@americanbar.org> (Sent: Friday, August 03, 2018 4:46 PM); c) Mark Murphy
 <markm@bazelon.org> (Sent: Fri, Jul 20, 2018 at 3:12 PM); d) Paula Frederick PaulaF@gabar.org (Sent: Thursday, July 12, 2018 11:25 AM); e) Eve Byrd <eve.byrd@cartercenter.org> (Sent: Thursday, July 7, 2018 10:15 AM)

- d) "Hello—I have done some programs on this in the past, but they were not totally focused on representing clients with mental illness. Atlanta Legal Aid/GLSP do some programming in this area, the Bar's Lawyer Assistance Program does an annual program (with some content on lawyers suffering from mental illness, not clients), the Barton Center at Emory along with the Bar's Committee on Children, the Criminal Law Section/GACDL does programming on representing criminal defendants who may suffer from mental illness. For each of these we do an ethics segment that covers the ethical responsibilities of a lawyer representing a client under a disability (but we would usually have dementia and Alzheimer's included). So there are small pieces of programming that cover this topic but I don't know of anything 100% on point."
- e) "Natalie--Thank you very much for your interest in this area. The work you are doing is so well needed. I am not aware of a curriculum."

An Internet search yielded a few articles and essays, but they leaned toward dementia, capacity issues and/or the ethics involved in representing clients with diminished capacity, and much less toward mental illness. Those that directly addressed the intersection of mental health and the law focused more on the criminal law intersection (i.e., forensic psychiatry and psychology); commitment procedures; and/or the rights of persons with mental illness to avoid involuntary holds.

A query to every state's legal assistance developer through the LSD-Talk listserv managed by TCSG, resulted in several developers referencing training materials on Alzheimer's disease and related dementias and the ethics of representing clients with diminished capacity. The Oregon developer recommended a seminar conducted by the Oregon State Bar in 2015. A review of seminar materials for a session entitled "Your Law Practice: Understanding Clients with Mental Illness" revealed that of the 168-page publication, only nine (9) pages were directly relevant to the representation of a client with mental illness; the rest were geared more towards mental illness as it relates to drug courts, investigations for drug courts, commitment hearings, and capacity issues.

PART TWO. GATHER INFORMATION FROM KEY INFORMANTS/EXPERTS

As noted in the Introduction, in order to identify how best to move forward to prepare legal services programs, particularly those funded through the Older Americans Act (OAA), to handle the representation of elders with mental illness, the overall approach to this project is twopronged.

The first prong, as described in this Part, is to seek advice/input of key informants/experts in geriatric mental health and legal representation of clients with mental illness to gain their perspective on such things as: 1) what legal providers need to know and understand to best serve this population; 2) things they would recommend as best practices; and 3) challenges in working with older clients with mental illness.

The second prong – a survey of OAA legal services providers -- is described in Part Three below.

I. Methodology for Gaining Advice/Input from Key Informants/Experts

Given the groundbreaking nature of this project, we elected to use key informant⁵ interviews to assist us in obtaining essential information about areas such as types of mental illness, training in mental illness, accommodations for clients with mental illness, ethics, and the many other issues we were eager to discover were needed to best serve this population. We were as anxious to find answers to questions we knew to ask, as we were to find out what questions we should be asking that we did not know to ask.

A. Identifying and Selecting Key Informants

Our initial field of key informants/experts was a group of thirty (30) and included —

- Law professors (especially those with an intersection of Mental Health & Law);
- Psychologists and Psychiatrists;
- Private Attorneys, Public Interest Attorneys;
- Geriatric Specialists: Clinicians; Neuropsychologists; and
- National Alliance on Mental Illness (NAMI) Advocates.

⁵ A key informant is an expert source of information. The key informant technique is an ethnographic research method which was originally used in the field of cultural anthropology and is now being used more widely in other branches of social science investigation. Marshall MN. The key informant techniques. Family Practice 1996; 13: 92-97 Last accessed online June 16, 2020 at https://pdfs.semanticscholar.org/df18/f52ec42d1fef4a149f474aeaad3cc51a4244.pdf

This initial list of 30 was labored over with criteria that we believed would be critical to us further on in our study. We also considered that not everyone we asked/invited would respond/consent and therefore for every one professional, we needed at least one alternate from whom we could obtain comparable information.

Having such an esteemed list of individuals with the backgrounds of these professionals was daunting to say the least. To narrow that list, we developed a set of criteria and used the criteria to examine their available individual biographies, curricula vitae, profiles and resumés. Those criteria included:

- Experience in working directly with persons with mental illness;
- Broad understanding of mental illness, including types of mental illness, causes, symptoms and treatments;
- Working knowledge of mental illness in older adults;
- Training and experience as a geriatric psychiatrist or geriatric psychologist (geropsychologist);
- Training and experience in elder law, or law and mental health;
- Experience in legal services and direct representation of clients;
- Background and experience in providing, creating or evaluating training/education of legal providers;
- Working knowledge and skills gained from direct provision of legal services to clients with mental illness, especially to older clients with mental illness. This includes knowledge of best ways to communicate, interact, and accommodate needs of clients with mental illness; and,
- Good understanding of the ethical issues involved in working with clients with mental illness and the evaluation of the influence of symptoms of mental illness on decisional capacity.

The field of thirty was eventually narrowed to sixteen and after two additional rounds of discussions, we agreed upon our final six key informants/experts and wrote letters requesting their assistance on the project (See Appendix 2 [pg.61] for sample letter of invitation.) Of those six, four participated in the study, and we are immensely grateful to them. (See Appendix 3 [pg.63] for information on the four key informants/experts.)

B. Conversations with Key Informants/Experts

We used our time with the key informants/experts to gain as much insight and wisdom from them as they were willing to share. We were clear that this was an attempt just to scratch the surface of this relatively unexplored issue. Their help would allow us to recommend to others how to proceed on this odyssey. We were overwhelmed by, yet remain forever grateful, for their generosity of time and expertise.

These conversations in turn helped us develop our survey for OAA Title IIIB legal services providers (described in Part Three below) and ultimately helped lead to the <u>Recommendations</u> (described in Part Five) that we offer from our work on this project.

As we worked to identify and select our key informants, we developed a set of questions to help guide our conversations with them. (See Appendix 4 [pgs. 64-68] for the full set of questions to guide conversations with key informants.) We provided the questions to them ahead of time and noted that not all questions would be relevant to each of them. We also provided each the option of not answering any question not within their particular field of expertise. This allowed each the comfort to address those areas within which she or he felt most at ease professionally giving us her or his best guidance.

It is also important to note that while these contacts with the experts began as semi-structured "interviews", they fairly soon became "conversations", in large part because each of these experts was passionate about the topic and wished to be free to simply talk informally.

All of our key informants/experts are zealous advocates for their clients and deeply engaged in the topic of working with persons with mental illness. All are fiercely committed to their work to protect the rights of persons with mental illness. Their overall recommendation is that people with mental illness must be valued and treated with respect.

II. Results/Learning from Input of Key Informants/Experts

Below are some of the key take-aways from the ideas and comments of our experts. They are organized according to, and in the order of, the questions that guided our conversations.

They are presented as bullet points in two columns.

- The left column reflects the comments of our two practicing attorneys who are very experienced in working with clients with mental health issues.
- The right column reflects comments of our two experts whose experience is more in research and teaching on these issues in academia.
- Where there was no response to a particular question, we so indicate at the appropriate spot.

Caveat: It is important to note that it was not our role to evaluate the comments of the experts, but simply to report what they said. We have made every effort to accurately reflect the comments and advice of each of the key informants. However, in the process of editing it is possible that we may have inadvertently misconstrued or misinterpreted something. We assume full responsibility and assure that any such error is without any deliberate intent.

Question 1. How would you define mental illness, particularly as it pertains to older persons, for an attorney or intake worker with little or no knowledge of mental illness?

Legal Practitioners:	Professors/Researchers:
 It is important to have a feel for	 It's important for lawyers to
the issues as opposed to using	recognize that there are
definitions.	gradations of mental illness and
 Practitioners must have enough	that having a mental illness
information to recognize and	doesn't mean a person is
understand the symptoms and	incompetent or cannot manage
issues of mental illness, as	their affairs.
opposed to labeling them.	 It is important to be able to
 People need to have a broad	differentiate mental illness from
understanding of psychosis and	dementia. Dementia may present
what it is, and particularly what it	a more permanent kind of
isn't. They should have an	incapacity, whereas people with
understanding of the big three:	some mental illnesses may be
schizophrenia, schizoaffective	experiencing a temporary period
disorder and bipolar type	of incapacity.
disorders. At least a baseline knowledge of these as well as major depression will help attorneys identify triggers, tactics	 I have no good definition. The attorney serving a client with mental illness should focus on functional abilities or lack of abilities, rather than a diagnosis,

and techniques to effectively problem solve with their client.	e.g., the ability to understand information, manipulate information, and/or communicate information.
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Question 2 (in three parts)

2.A. What level of understanding of the characteristics of various mental illnesses is needed for legal providers to deliver effective services to clients with a mental illness?

2.B. What **training is required** so they can understand and **recognize signs and symptoms** of mental illness, including the ability to receive instructions or participate in their case?

2.C. Should this training include a description/discussion of other **circumstances that may mimic or exacerbate mental illness,** e.g., PTSD or trauma, that attorneys should be aware of and sensitive to?

Legal Practitioners:	Professors/Researchers:
2.A. No response.	2.A. Legal providers don't need course work to differentiate between mental illnesses or an extensive scientific understanding of particular mental illnesses. They need to understand that mental illness is a real thing, that it <i>is</i> an illness. They need a general level of sensitivity and the ability to assess when there is a significant impairment.
2.B. Each organization needs to have at least one person with an "expert" level of knowledge in serving clients with mental illness. Clients that appear to have a mental illness should be referred to that person.	2.B. No response.
2.C. There are many things that can exacerbate a person's mental illness and that need to be included in training.	2.C. The teaching point here is that lawyers need to look at the history of a person's mental health problems.
• It is important that we are cognizant of what we do from the minute the client walks in the door to avoid making things worse instead of better.	

 The first thing attorneys need to understand and appreciate is what it may have taken for the client simply to get there. We don't tend to view mental illness in the same way that we view physical disability. 	
 It's important not to draw conclusions about the client's perspective or goals. 	

Question 3. What might be the **consequences for the client if an attorney is not sufficiently educated** about mental illness and its effects on the client's ability to participate in their case? (e.g., effect on discussions between the client and the legal provider, the client's ability to make informed decisions, or the client's ability to participate in an administrative hearing or court forum)?

 Without sensitivity and awareness, it is possible to lose the trust of clients with mental illness very quickly. Being aware of your own responses to the client and how 	 Person centered care is critical. You must get to know the client as a person, spending time with
 Every office staff person the client interacts with is an opportunity to gain or lose the client's trust. Treating the client with respect, dignity and kindness can go a long way. This may mean validating and apologizing for the client's upset, even when staff feels they have done nothing wrong. 	 them at various times of day so that you may properly assess changes in their behavior. Beware of ageist attitudes, particularly with depression. Depression should not be seen as a normal part of the aging process. It should be treated. Older adults in general are just as satisfied with their lives and have equal, not greater, rates of depression as younger adults. A risk is the attorney takes on both the role of attorney and the role of attorney and the role of decision-maker for the client, and that may not be consistent with what the client would have wanted.

Question 4. What are the greatest challenges you see for legal providers who represent clients with mental illness?

Legal Practitioners:	Professors/ Researchers:
 Behavioral issues may hamper representation. It is sometimes difficult to get clients with mental illness to pay attention and take needed actions. 	 Confidentiality is one specific challenge because if you are unable to obtain the information you need from your client, you have to figure out how to interact
 Persons with mental illness are often stigmatized and 	with other professionals to obtain the needed information.
stereotyped, and their behavior may be erratic and fall outside of social norms making them unappealing and difficult to like.	 It may be difficult to determine when you need inter-professional assistance for your client and how to obtain it.

Question 5. Given that the focus of this project is on the delivery of legal services to older individuals with mental illness, **do older persons with mental illness have specific challenges** not generally experienced by younger adults with mental illness? **If you feel** there are specific challenges more likely to be faced by older adults with mental illness, could **you elaborate?**

Legal Practitioners:	Professors/ Researchers:
 Sometimes the situation is the	 For older adults with a history
client may be too old, ill, and frail	of mental illness, it is important
and absolutely nobody will take	to examine that history –
them. There is nobody that will	diagnosis, treatment received,
deal with them. There is nobody	and how did they do under
that will tend to their needs.	treatment.
There could be difficulty locating a	 If this is the first episode, there
facility for them that is legitimate.	needs to be an effort to find
They end up in a less than ideal	triggering events, such as a
facility. Thus, for the older client	recent loss, either due to the
it then requires that:	death of someone close or loss
• The practitioner must know	of functioning due to a medical
as much about how the	condition.

system can fail as about how it works. When the system fails, clients may end up in a much worse situation with a greater need for legal assistance;

- Sometimes a mental health facility may be the only good option for care but barriers to payment for that care are limited by policy, regulations or other challenges. The possibility of losing needed care as a result of these challenges poses a serious risk to the client.
- Older clients, knowing their own situation better than anyone, [having lived with it longer] may proactively try to seek psychiatric help in advance of a crisis, only to be told they will be fine and released back home. This could result in the possibility of the client causing harm to self or others and the legal consequences that come from causing that harm.

- Older adults tend to be less informed about psychiatric treatment and less willing to seek or undergo treatment. They may be less willing to be proactive.
- For older adults, there is typically a history and with that history a string of losses not typically found with younger persons. These losses, e.g., loss of spouses, children/ relatives/close friends, jobs or positions, health, homes, etc., tend to exacerbate the effects of the mental illness and add additional issues.
- Older people may have exhausted their family through death or may have driven them away, especially if they have had a mental illness for a long time, so family is not there to provide support.
- You may want to distinguish people who have had a mental illness for all, or most of their life, from people who have late onset mental illness.
- If trying to determine what a client would have wanted when able to make decisions, it may be easier to examine past decision-making if the client has only recently developed a mental illness. People who have had mental illness their entire life may not have a reliable record of decisions that reflect their true values.
- It is extremely important to remember that mental health

bit slower to get better.

Question 6. In cases of **late-onset mental illness, are there important differences/challenges** that legal providers should be

prepared to address?

Legal Practitioners:	Professors/ Researchers:
 What appears to be late onset of mental illness may instead be late onset of symptoms. 	 It is important to distinguish between people who have had episodes of depression earlier in their life and people who are suffering a first-time, late onset depression due to a loss in their life.
	 In contrast to what you might think, it is not always easier to treat late life depression.
	 Other medical problems and medications can confuse diagnosis with older adults. Clear assessment is needed.

Question 7. Is safety an issue that should be addressed in training legal providers to represent older persons with mental illness?

Legal Practitioners:	Professors/ Researchers:
 The first thing that has to be	 There are many myths about aging
overcome is the idea that	and mental illness.
somehow your safety is at risk,	 People with mental illness are
because I have never had that be	much more likely to be victims of
an issue.	crime than perpetrators of crime.
 It can happen, but it is a myth that persons with serious mental 	 Discussing safety is a worthwhile consideration, if only to put the legal providers at ease, if they

illness are violent. This is even more unlikely with an older adult.	have not worked with persons with mental illness.
 In the small percentage of cases where it happens, it is almost always during a psychotic break when they don't know what's going on, and when the person is confronted with law enforcement. 	 It is rare for there to be a risk of physical danger and letting providers know this, will put them at ease.
 It is a bigger problem for us to worry about someone being dangerous than them actually being dangerous. 	
 In almost all instances, providers should use common sense and standard procedures to stay safe, as they would with any client. 	
 I'm not sure you can teach someone not to be biased against the mentally ill. 	
 Training needs to convey to the depth of someone's soul the understanding that the behaviors being manifested by a person with mental illness are not to annoy you. It's not something they are doing because they want to. 	

Question 8. What if anything different, do legal providers need to do **to enhance their interviewing skills** to prepare for clients with a mental illness?

Legal Practitioners:	Professors/ Researchers:
 Start by talking, having a conversation. You must speak with the client as if your 	 Older adults may process information a bit slower, so slow down the pace of the interview.
conversation is completely normal and then you will get a raft of information that you need	 Make sure the person understands your questions.
in order to help the person.	 Have the individual reflect back to you the questions you have asked

 First, from the very beginning, it should be a conversation, not an 	to make sure they correctly understood the question.
interview. The attorney has to shift their mind and be less linear; they have to get away from thinking they must get "X" specific information in "Y" order.	 Medical schools and nursing schools are better at teaching interviewing skills than law schools.
• Be prepared to protect the clients from stress, hurling yourself between them and the stress if necessary, and remember by its very nature, a legal situation is stressful.	 Consider that sometimes the issue may be one of hearing or visual deficit and not necessarily cognition: Make sure they have their hearing aids; Amplify your voice;
 Let the focus be less question/interview oriented and more conversation driven. Steer the conversation eventually to the questions you need to have answered. 	 Enunciate your words; Slow your speech; Use large print.

Question 9. What specific skills, knowledge or training can help **to foster mutual trust** between the attorney and the client with a mental illness?

Legal Practitioners:	Professors/Researchers:
 Listening skills are crucial. A person with mental illness, 	 Learn to exercise patience.
perhaps especially if they are older, is used to not being heard.	 Sometimes it may be necessary to ask the
 Know how to shift the power dynamic to empower the client: Don't meet across a desk; Don't use a computer; and have a notepad off to the side. 	 same question several ways, several times to obtain an accurate answer. Practice makes perfect o Sometimes observing,
 Have beverages and food available to help create a bond. 	practicing, and having someone critique your practice improves
 Be amenable to breaking up appointments rather than just plowing through. 	the skill.

 Learn to recognize signs that the client is getting worn out or agitated. Take it upon yourself to suggest that you need a break or that you would like to stop and schedule another appointment. 	
 Respect is essential: Respect the client's personal space. Be careful not to touch them; keep your distance and let them set the distance, e.g., be aware if they are moving away. Respect the client's 	
possessions. Often people with psychosis will carry bags or items with them. Understand that that bag or those items are extremely important to them and be very respectful.	
 Respect and honor your client's understanding of and methods for coping with their mental illness. 	

Question 10. What, if any, adaptations might be required in a **legal provider's office/intake site** to accommodate the needs of a client with a mental illness? Similarly, what accommodations might need to be requested of the **administrative forum or court** to meet a client's specific needs?

Legal Practitioners:	Professors/ Researchers:
 In a Provider's Office/Intake site Be cognizant of what the client sees when they walk in the door; is it crowded and/or noisy? Arrange times when it will be less crowded. Create an informal meeting environment to make clients 	 Because an older person may tire more quickly and their performance might suffer, be prepared to break up interviews into smaller time frames. Some people with mental illness have an inability to sit still: Be sensitive to the need to
most comfortable.	accommodate nervousness,

Control the lighting to the order of	
 Control the lighting to the extent possible. Fluorescent lighting is a 	fidgetiness and an inability to sit still;
problem.	 Possibly colors and lighting
 Accommodate the needs of the client wherever possible in the most respectful way possible. Be cognizant of their need to be heard and be understood. 	could cause problems for some.
 Accommodations might include: Meet in a place and at a time that alleviates crowding; Be on the lookout for the person and meet them as soon as they arrive; Take responsibility for the client's upset onto yourself. Apologize even if it wasn't your fault; Work with and around the client's schedule not yours; Go slow if necessary; Reschedule if necessary. 	
In Court or Administrative Forum	
• Plan in advance with the client.	
 To the extent possible control any negative environmental factors: 	
 Anticipate and prepare your client for what is going to occur; 	
 Talk to the court coordinators in advance to tell them you have a client with a serious mental illness; and, 	
 Try to get a room at the court set aside where you and your client can be alone. 	

Question 11. What **community services or resources** should legal providers be knowledgeable about when representing clients with mental illness? When is it **appropriate to refer a client** to supportive services in the community?

Legal Practitioners:	Professors/ Researchers:
 You need to know everything you can about community services and resources. 	 Housing is very important. You want to be aware of housing resources, financial resources, and transportation resources because older people are typically concerned about overburdening family members to transport them.
 There is only so much a lawyer, by herself, can do. If the person seems open and they have a question or issue, it is 	
 It may depend on whether the program is equipped to access wrap-around services and whether lawyers are skilled in discussing additional services with clients. It is important not to get bogged down in the referral to the detriment of providing legal services. 	 Some clients may need a team approach to meet their needs. At the same time, we need to be very wary of being paternalistic.
	 Attorneys should push the idea that they are working to know what the older client wants, rather than imposing a best interest standard on them.
	 Psychiatric Advance Directives are also important and good for older adults as well as younger adults.

Question 12. Ethical Issues: Are there any circumstances when the client with mental illness **cannot be represented** because of the severity of their mental illness and **what should a legal provider do** in that instance?

Legal Practitioners:	Professors/ Researchers:
 Very rarely is a client so	 This is where the Psychiatric
incapacitated that I cannot	Advance Directive can be
represent them. However, there	beneficial.
may be rare instances when the	 The Code of Professional
person may be so ill, they can't	Responsibility will likely have to
make their own legal decisions.	be relied on here. There is a
Other ways have to be used at	particular provision for
that point to address the	answering ethical questions for
individual's needs.	dealing with clients with
• There will be times when the	impaired capacity.
client asks the attorney to do	 We hope there are no
things that are not in their best	circumstances where a person
interests. It's a "sticky wicket"	could not be represented
because I feel that the attorney's	because of their mental illness;

ethical obligation is not to just do whatever the client asks.

- I believe the attorney should have a conversation with them to help identify their goal and, in an effort to help them achieve that goal, to point out what they are missing.
- There are some things an attorney cannot ethically do, even if the client asks. In this situation, the attorney should continue to help them try to achieve their goal by pointing out what they are missing.
- Always assume capacity. I have not found it to be the case that we cannot represent someone.
 Some lawyers are working with biases they don't even know they have, and automatically assume that if a person has a serious mental illness, they cannot make decisions. That is not true.
- I think the ethical component is in the opposite direction, that is, always assume something can be done. We need to think what can I do and how can I help the person, rather than "I can't communicate with this person." It's not from ill intent; it's just not understanding that we can do so much if we change our perspective and how we handle the interaction.
- Always try to employ a partial if not full Psychiatric Advance Directive.

if they have a legal need, someone has got to be able represent them.

- Focus on doing what you can for the client.
- Keep a close eye on the ethical issues to avoid ending up being both attorney and decision-maker.

•	If the person is capable of saying something they do or do not want; that's something.	
•	Pressing the pause button and rescheduling is always a reasonable step to take. There are days when it is not a good day for a client with mental illness. Pressing forward is detrimental. It does not mean the client does not have the capacity to proceed; it means that day is not the day to proceed.	

Question 13. When, if ever, should a legal provider **push a client to seek counseling or treatment** for a mental illness or <u>suspected mental illness?</u>

Legal Practitioners:	Professors/ Researchers:
 Only if you can do it without offending; otherwise absolutely not. The way lawyers handle this is critically important. The danger is attorneys may try to tell the client what to do, resulting in making the client angry or feeling offended, and the client may terminate the relationship. 	 Older adults are their own persons. Maybe get family members who can encourage them. Only force the issue if they're showing evidence of incompetence and then the courts take over. Depends on your definition of push If that's inform and recommend, then yes. However, first, investigate to make sure the resources are there and available to help. Stop if it's coercion or undue influence.

Question 14. Are there any different ethical considerations when working with clients with mental illness than with clients with dementia? Are the precautions for attorneys the same?

Legal Practitioners:

- I don't think so. Whether it is a client with mental illness or with dementia, it is important not to lie to clients or confront them with their inability to understand, but instead gently lead them to where you want them to be in order to achieve their goal.
- Deal with the immediate solution. Don't confront them with their inability to understand.

Professors/ Researchers:

- Biggest difference is that with dementia you know the person's ability to make decisions and to process information will go downhill.
- Mental illness is chronic, but you can have periods of good health.
- Older clients with a lifelong history of mental illness have the benefit of a history of dealing with their illness that can help the attorney understand them and their needs.

Questions 15-18: Psychiatric Advance Directives and Other

Tools – What Do Legal Providers Need to Know to Assist

Clients with mental illness?6

- 15. **How and when** might a legal provider use psychiatric advance directives?
- 16. If you use psychiatric advance directives, **how often do you use them**?
- 17. Do you recommend that **all legal providers be trained** on them?
- 18. Are there **other kinds of documents or legal tools**, besides psychiatric advance directives, that are particularly useful when working with clients with mental illness?

Legal Practitioners:	Professors/ Researchers:
 The Psychiatric Advance Directive	 Clients with the mental capacity
is a critical document: It can be added into a medical	should execute Psychiatric Advance
advance directive;	Directives.

⁶ Psychiatric Advance Directives are defined by the Substance Abuse and Mental Health Services Administration (SAMHSA) as a legal tool that allows a person with mental illness to state their preferences for treatment in advance of a crisis. Substance Abuse and Mental Health Services Administration: A Practical Guide to Psychiatric Advance Directives. Rockville, MD: Center for Mental Health Services. Substance Abuse and Mental Health Services Administration, 2019. While, all states may not currently have or honor PADs, all states do have some form of health care or medical advance directives whether they are Living Wills allowing one to choose to have life support withdrawn or withheld in certain situations or Health Care Directives allowing one to appoint an agent to carry out designated health care decisions on his or her behalf.

III. Final Question (19): What else? What do we need to know that we don't know to ask?

Our final question to our experts was:

"What haven't we asked that we should and what are your responses to that question?"

We are handling this final question in a slightly different manner from those above. Here we **focus on practitioners' responses** which have not been previously addressed **in order to highlight important points** made by them that we did not even know to ask about. Responses from the Professors/Researchers reiterated or emphasized their responses to earlier questions, and we do not repeat those here.

The practitioners focused on the groundbreaking nature of this project, and the serious need for more work to be done on the topic. This focus serves as a good way to end our discussion of this section.

Their two final points were:

1. Advocates need to know as much about how the systems in place to support persons with mental illness DO NOT WORK as about how they do work.

Both legal practitioners talked about the ways in which the system in place to provide support/care for persons with mental illness is broken and how it can fail and hurt them. As advocates for older persons with mental illness, there is real need for Older Americans Act attorneys, and other civil legal services attorneys to be aware that these systemic problems exist and to be ready to protect clients from them. For example, they need to know how to counsel clients and families:

- on how and when to call the police and what information to provide:
 - While there are certainly officers who know how to diffuse a situation where a person with mental illness is acting out, many have not been trained and do not have these skills;
 - Police/public safety professionals are very often first responders to a mental health crisis. If they are unprepared and/or inadequately trained, they may exacerbate rather than diffuse the situation. This may lead to possible injury or death of first responders and/or of the person with mental illness. The result too often is a great likelihood that criminal charges will be levied against the person with mental illness and the person will be incarcerated.
- on how to get someone with mental illness who wants treatment admitted to a hospital/treatment facility, including what language to use:
 - While laws and regulations differ from state to state, typically, in order to be taken to the hospital and treated you have to be a danger to self or to others;
 - Limited quality treatment facilities are part of the problem as are limitations on what insurance will cover. One of the difficulties of caring for people with mental illness in the community is the limited supply of community resources and services, particularly housing. It would take about one quarter of the money we put into jails and prisons to make a significant impact on housing and supports to solve many of the problems of persons with mental illness.

2. There is a baseline level of expertise required of OAA Title IIIB and other civil legal services programs and attorneys.

Both legal practitioners talked about the specialized knowledge that they have gathered through their many years of working with people with mental illness. They noted that it is not a specialty that many legal services providers have, but there is a growing need for it. This led to in-depth discussions with them both about what we should be able to expect from the lawyers/programs that represent people, particularly older people, with mental illness.

Although both practitioner experts addressed the question in different ways, the conclusion from their remarks carried common themes. A good legal services program owes it to their clients to train every one of its lawyers to be able to provide effective representation to clients with mental illness. Anything less is discriminatory and is a violation of the Americans with Disabilities Act. Part of the problem of discrimination is that we tend not to think of mental illness and its manifestations in the way that we think of other disabilities. For example, if a person is an amputee this means there is a mobility issue, and the attorney needs to provide accommodation for the mobility issue. However, we tend not to think of mental illness in the same way. It is important to be sensitive to the fact that *mental illness* is a disability and must be accommodated just as we would accommodate a physical disability. Legal services providers need to know the signs and symptoms of mental illness, how best to communicate with clients with mental illness and how to accommodate their needs in the office or at a hearing.

If at all possible, programs should also have lawyers on staff with an even greater level of training and expertise in representing clients with mental illness. These persons need to be able to bridge the gap and walk back and forth between the legal and the mental health worlds, as there is generally no bridge there.

Having examined the input/comments of our key informants/experts, we **turn now to Part Three** for input from OAA Title IIIB providers obtained through a survey.

PART THREE. GATHER INFORMATION FROM OLDER AMERICANS ACT LEGAL SERVICES PROVIDERS

I. Introduction/Background of Survey

As noted above, this project is a *first-ever* attempt to gather information on the awareness and preparedness of our Older Americans Act (OAA) IIIB legal providers to represent older persons who present with mental health issues. While older persons with mental illness are clearly an important target group under the Older Americans Act, little attention has been paid them in the past. And, based on our preliminary inquiries, almost nothing has been done to prepare OAA legal providers (and other providers of civil legal services) with the necessary skills, awareness and support to provide effective and successful representation of these clients, even as the numbers/percentages of elders with mental health issues are increasing.

Thus, in addition to the interviews with key informants (experts) in geriatric mental health/mental illness described in Part Two above, a critical piece of the project was to survey Title IIIB direct providers of legal services in a number of select states to gather baseline information on such things as:

- their experience in working with older persons with mental illness;
- their knowledge and understanding of working with older persons with mental illness;
- challenges they face in working with older persons with mental illness; and,
- their training or lack of training in working with older persons with mental illness.

II. Overview of Methodology

Because there is no list of IIIB legal services providers nationwide from which we could draw a sample for the survey, our first challenge was to find a method to contact a meaningful number of providers. We decided the best method was to seek assistance from select State Legal Services Developers (LSDs), asking them to pass the survey on to their providers across the state and request their providers to respond to the survey. States selected were based on such things as:

- geographic and demographic diversity;
- the state having a developer who is actually doing development work, something not every state has;
- the developer having a reasonable amount of time to do that work; and,

• the likelihood the state developer would be willing and able to disseminate the survey to their providers.

After thorough consideration, thirteen States/developers were selected, including

- 1. California, Chisorom Okwuosa & Carmen Gibbs
- 2. Florida, Sarah Halsell
- 3. Georgia, Natalie Thomas
- 4. Hawaii, Cristina Valenzuela
- 5. Iowa, Ben Mulford
- 6. Louisiana, Jane Arieux Thomas
- 7. Maryland, Lydia Williams (former developer)
- 8. Michigan, Dawn Jacobs
- 9. New Jersey, Denise Lyles
- 10. Oregon, Christian Hale
- 11. South Carolina, Nicole Hair
- 12. Utah, Jean Boyack, and
- 13. West Virginia, Jacqueline Proctor

Total number of providers in the 13 states was just over 150, ranging from states with one statewide provider (West Virginia) to 38 providers in CA. (Please see Appendix 5 [pgs. 69-71] for a sample of the letter requesting assistance from the selected developers.) The letter to developers included a sample note they could personalize and send on to their providers.

III. Overview of Content of the Survey

Given the groundbreaking nature of the project, project investigators spent several months drafting and editing the survey. To reduce respondents' completion time, investigators kept open-ended questions to a minimum. In our instructions we explained:

While you don't have to respond to open-ended questions if you don't have time, we urge you to do so and also urge you to insert any comments on the last question (Q. 28), which is completely open-ended.

A second, and extremely important task in drafting the survey was to come up with a working definition of the term "mental illness" so that all respondents would be working with the same definition. *Note*: Interviews with key informants failed to identify a universally accepted definition of mental illness. Our working definition is below:

For purposes of this survey, we define mental illness as:

a mental, behavioral or emotional disorder (excluding developmental and substance use disorders) resulting in serious functional impairment, which substantially interferes with or limits one or more

major life activities including work, social, and family life. For survey purposes we are talking about something that rises to a level that it significantly impacts a client's thinking, emotion and behavior, including their ability to be represented legally. This is often categorized as "**serious mental illness**" and examples include major depressive disorder, schizophrenia and bipolar disorder.

Survey questions were divided into **four broad categories** as follows:

- 1. Questions about any **professional experience** the provider has in representing persons with mental illness either older or younger persons.
- 2. Questions about **any personal experience** the provider may have with persons with mental illness of any age, as well as any **preconceptions** the provider may have about such persons.
- 3. Questions about the provider's **knowledge and skills** regarding how best to represent/interact with older clients with mental illness, as well as about **training/resources** the provider has received, or the provider feels are needed to be able to serve effectively older clients with mental illness.
- 4. A final question allowing the provider to give us **any additional comments** that would add to our understanding.

IV. Specific topics/questions addressed in the Survey (Organized by Topic Groupings).

When finalized, the survey included a total of twenty-eight (28) questions. To a limited extent, we patterned the areas of inquiry to dovetail with the topic areas addressed in our interviews with key informants/experts so that we might look at similarities and differences between responses from the experts and responses from direct service providers. (See Appendix 7 [pgs. 73-84] for a complete copy of the Title IIIB Survey Instrument.)

Of the 28 questions asked in the final version of the survey, they can be broadly categorized under the nine (9) groupings outlined below

A. Question 1. General inquiry regarding preparedness:

- inquired generally about how prepared providers believe they are to address needs of clients with mental illness.
- **B.** Questions 2-3, and 5. Extent of experience with persons with mental illness, both professional & personal:
 - asked about extent, both professional and personal, of experience with clients/persons with mental illness, and asked about **persons** of any age, as well as those aged 60+.

- C. Questions 6 & 7. Impact of personal experience on attitudes:
 - asked if personal experience made a difference in their attitude, and for those without personal experience, asked if they have preconceived notions of persons with mental illness.
- D. Questions 4, 8-10. Knowledge of types of mental illness, common manifestations/symptoms and importance of training:
 - asked about knowledge of common manifestations/symptoms of mental illness and how to address their impact on representation; also asked about importance of training on manifestations/symptoms.
- E. Questions 11-19. Knowledge and skills in a variety of aspects of working with persons with mental illness and importance of training:
 - asked how providers rate their knowledge and skills in working with persons with mental illness and about how important they believe training is on those skills. They were asked specifically about skills in:
 - **Communication;**
 - Interpersonal interactions; and
 - Accommodations that may be needed.
- F. Questions 20-22. Psychiatric Advance Directives and importance of training:
 - asked about knowledge of psychiatric advance directives, and about any training received and about the importance of training in this area.
- G. Questions 23-25. Knowledge, awareness and skills on ethical issues and importance of training:
 - asked about knowledge, awareness & skills; about any training received on ethical issues, and about the importance of training on ethical issues.

H. Questions 26-27. Knowledge of community resources:

- asked about knowledge and awareness providers have of other community resources that could be helpful when working with persons with mental illness.
- I. Question 28 (the final question)
 - asked for any additional thoughts or comments respondents would like to share.

V. Survey Responses Received from IIIB Legal Providers

We received a total of 52 responses to the Survey of IIIB legal providers, providing a good baseline on which to build in the future, and a good body of

information about their level of preparedness to serve older clients with mental illness and the dearth of training and resources needed to prepare them to serve this clientele.

Further, an unanticipated, but welcome result was that a number of state legal services developers responded to our request for their assistance, indicating how important they think the project is. See for example, a quote from the Hawaii developer at the conclusion of this section of the report.

VI. Overall Observations from Survey Responses

In general, the survey focused on <u>four areas of inquiry</u>.

- 1. The general level of knowledge, experience and understanding of respondents with respect to the specific topics identified in the survey as related to working with older adults with mental illness.
- 2. The level of training respondents received with respect to each of these topics.
- 3. The respondents' assessments of the importance of training on these specific issues.
- 4. Respondents' personal and professional experience with persons with mental illness and their knowledge of additional resources in the community.

Below we summarize our observations of responses to these four areas.

1. Knowledge & Awareness of Issues Related to Working with Older Adults with Mental Illness

With one exception, the survey revealed that a **great majority** of respondents **reported at least SOME knowledge**, **awareness**, **preparedness or understanding** of the specific issues related to working with older adults with mental illness. These issues included:

- preparedness to handle a client with serious mental illness (84%);
- understanding of common manifestations of symptoms (94%);
- understanding of how to communicate with persons with mental illness (98%);
- knowledge of how to maximize interpersonal interactions with persons with mental illness (94%);
- knowledge of accommodations for working with persons with mental illness (96%); and,
- understanding of ethical issues involved in working with older adults with mental illness (94%).

The <u>one exception</u> to self-assessment of knowledge and preparedness was in the area of psychiatric advance directives (PADs). Only 43% of respondents

said they had "some knowledge." The same percentage (43%) said they had "no knowledge."

In contrast, **EXTENSIVE knowledge, awareness, preparedness or understanding** were **reported much less frequently** for the same list of issues as above. Only 10% to 41% of respondents reported extensive knowledge or preparedness:

- definitely prepared for working with a person with serious mental illness (20%);
- extensive knowledge of types of mental illness (25%);
- extensive understanding of common manifestations of mental illness (12%);
- extensive understanding of communicating with respondents with mental illness (37%);
- extensive knowledge of techniques for interpersonal interactions with clients with mental illness (41%);
- extensive knowledge of how to make accommodations for persons with mental illness (31%); and,
- extensive knowledge or use of psychiatric advance directives (only 10%).

Caveat: In analyzing these responses, it is worth pointing out that we decided to use the survey not only to investigate the current status of respondents' knowledge and experience, but also to use it as an opportunity to do some education of respondents. To do this, we included examples in many of the questions of the kinds of skills or knowledge we were asking about. For example:

- at the end of the question on how they would rate their own knowledge of types of mental illness, we said: "For example schizophrenia, bipolar disorder, anxiety disorder, depression, delusional disorder, trauma related disorder";
- at the end of the question about knowledge of communication techniques, we gave examples of communication strategies like "e.g., listen carefully and actively, affirm that you hear and understand them; don't condescend or be antagonistic or confrontational; avoid legalese, etc.)".

Our attempts to educate by providing examples may have prompted respondents to answer that they had more knowledge than they actually do. It is possible that a respondent might think to themselves, 'well, I do some of those things sometimes.' While it is good to hear that a legal services provider's natural reaction may be to adopt some of these techniques, it DOES NOT necessarily equal having real skills in working with these clients. Obtaining those skills would require training. We are convinced, training in these areas would increase the intentionality of the lawyer's use of such techniques. In fact, as discussed below, our examination of the training received by respondents indicates that training in these areas is minimal.

2. Training Received on Issues Related to Working with Older Adults with Mental Illness

While many respondents indicated that they had **some knowledge** of specific strategies and topics explored in the survey, **the majority** said they **had received no or only some training** on these issues. This included:

- No or only some training on common manifestations or symptoms of mental illness (94%);
- No or only some training on communication skills (90%);
- No or only some training on interpersonal interactions (88%);
- No or only some training on accommodations (84%);
- No or only some training on ethical issues (76%); and,
- No or only some training on psychiatric advance directives (96%).

Extensive training on these issues was rarely reported. This included:

- Extensive training on common manifestations of mental illness (4%);
- Extensive training in communication skills (10%);
- Extensive training on interpersonal interactions (12%);
- Extensive training on accommodations (16%);
- Extensive training on ethical issues (24%); and,
- Extensive training on psychiatric advance directives (4%).

3. Assessment by Respondents of Importance of Training on Issues Related to Working with Older Adults with Mental Illness.

The biggest take away from the survey was that there was **almost unanimous agreement on the importance of training and resources** <u>in all topic areas</u> addressed in the survey. At the same time, as noted above, relatively few responded that they had received that training. For the issues identified by the survey, over three quarters of respondents thought they were very important areas for training. The exact percentage of respondents saying training is very important are given below:

- Common manifestations/symptoms of mental illness (84%);
- Communicating with persons with mental illness (84%);
- Interpersonal interactions with persons with mental illness (86%);
- Accommodations for persons with mental illness (86%);
- Psychiatric advance directives (76%); and,
- Ethical issues in working with persons with mental illness (94%).

As a whole, we believe the responses to survey questions about knowledge, training and the value of training indicate that respondents don't have the in-depth understanding and skills they need. We further believe that they recognize the vital importance of training so that they can be more intentional in their work with older persons with mental illness.

4. Respondents' Personal and Professional Experience with Mental Illness and Their Knowledge of Available Community Resources

We were somewhat surprised at the extent to which IIIB legal providers have both personal and professional experience with persons with mental illness. Eighty-four percent (84%) of respondents reported having worked with older persons with mental illness <u>at least</u> <u>occasionally</u>. Twenty-two percent (22%) reported <u>frequently</u> working with older persons with mental illness. Those numbers are even higher when asked about serving clients of any age with mental illness. Almost 50% of respondents said that they <u>frequently</u> work with clients with mental illness. Over 90% of respondents had personal experience interacting with persons with mental illness.

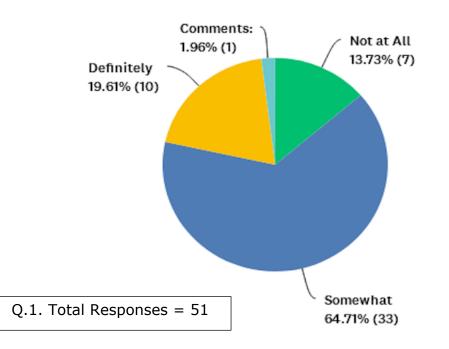
Further, in general, respondents demonstrated a good knowledge of additional resources for clients with mental illness, available in their community. Only one respondent had no awareness or knowledge of the resources available to persons with mental illness. The remainder of respondents named from one resource to a long list of resources in their community. See the discussion at Q. 27 on Resources [pg.49].

VII. Responses to Individual Questions Organized by Nine Broad Topic Groups

As noted, we received a total of 52 responses to the survey. For most questions, there were 51 respondents. The number responding to each individual question is noted in the text boxes below the graphs.

As also noted above, survey questions fell into nine broad topic areas/groupings. Below, we briefly describe responses to individual questions organized around those topic areas.

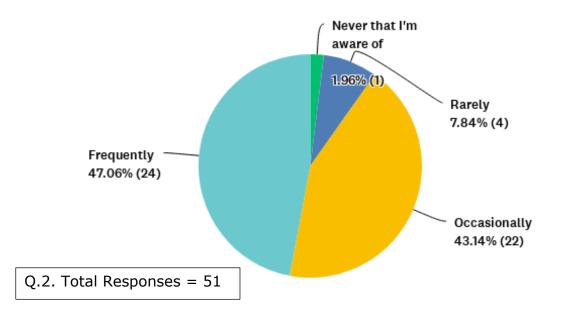
Group 1. Response to Question 1. General inquiry regarding preparedness. We began the survey with three scenarios that might confront a IIIB legal provider when first meeting with an older client with mental health issues. *(The survey scenarios are provided in Appendix 6 [p.72].)* We then asked how prepared generally the IIIB providers believe they are to address needs of clients with mental illness. Responses are shown in the pie chart below.



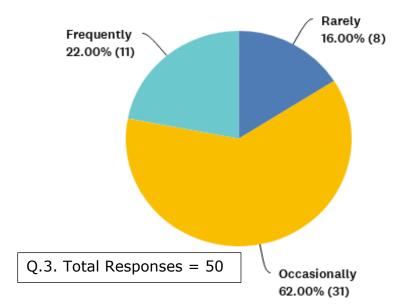
One Comment was received on Question 1. I'm prepared to address Client's Needs, but in each of the scenarios, Client lacks the capacity to retain my services or, if already retained, to provide me with meaningful assistance to represent Client. As required by Court rules, I will take reasonably necessary protective action for Client's benefit

Group 2. Responses to question 2-3, and 5, regarding extent of professional and personal experience in working with/interacting with persons with mental illness, both with persons of any age, as well as persons age 60+.

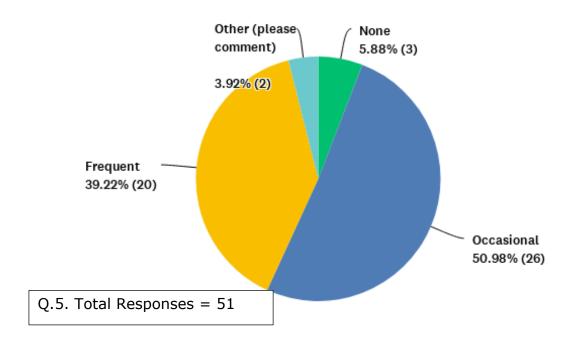
• <u>Question 2</u> asked respondents about how often they have had professional experience with clients of any age that had mental illness or that they suspected had mental illness. The responses are illustrated below:



• <u>Question 3</u> asked respondents how often they have had professional experience with clients age 60 and older with mental illness. Data from the 50 responses are illustrated below:



• <u>Question 5</u>: Fifty-one (51) responses were received regarding how often the respondents have had *personal experience* interacting with persons with mental illness (friends, family, colleagues). Results are shown below.



The two respondents who replied "Other" commented: (1) Worked in a patient' rights legal clinic at a large mental health hospital a number of years ago. Everyone was there because they were believed to be a danger to themselves or others by virtue of a mental disability; and (2) I have had staff members with such diagnoses as well as close family members.

Group 3. Responses to Questions 6-7 regarding impact of personal experience on attitudes.

• <u>Question 6</u> asked whether personal experience made a difference in their attitude or in how they interacted with persons with mental illness. Responses are illustrated below:

100%	16.67%	
80%	2.08% 10.42%	
60%	33.33%	
40%		
1070		
20%	37.50%	
0%		

Q.6.Total Responses = 48

Prompted me to learn more about mental illness and its manifestations

Caused me to have a more positive attitude about persons with mental illness

Caused me to have a more negative attitude about persons with mental illness

Caused me to become an Advocate for them/their rights

Caused me to become a provider of health, social and or support services for them Other (please describe)

Of the 16.67% who responded "Other" to Question 6, eight comments were received as follows:

1. Three of the commenters indicated they would have checked All of the Above (except for the one about having a negative attitude) if that had been allowed. And one of the three went on to say I have learned to "stay in the moment" with the client; to convey that their reaction/behavior is credible and to try to create space for them to have their reactions without feeling judged or controlled. Sometimes, this may mean delaying the interview or appointment until the client's condition is no longer acute.

2. Prompted me to learn more about mental illness and its manifestations; caused me to become an Advocate for them/their rights

3. My personal experience with family, friends and colleagues with mental illness has not affected my interactions with or attitude to other people with mental illness. I treat all people with a disability with the respect which is due to all people.

4. Caused me to be more sensitive to persons with mental

illness. However, my attitude is sometimes negative and sometimes positive.

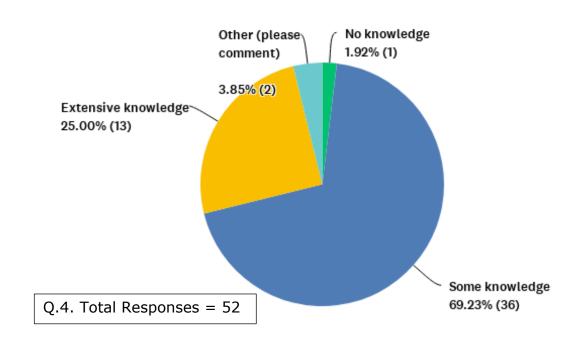
5. I think that it has made me more cognizant that I need to be looking for and adjusting how I interact with folks based upon possible mental illness.

6. Provided me with more awareness of mental illness, but I wouldn't say it gave me a more positive or negative attitude.

 <u>Question 7</u> asked (as follow-up to question 5) of the three respondents who said they have had no experience with persons with mental illness, whether their lack of experience left them with preconceived ideas about such persons. One responded, 'Yes', and two responded, 'No'.

Group 4. Responses to Questions 4 and 8-10 regarding knowledge of types of mental illness, common manifestations/symptoms and how to address their impact on representation, as well as the importance of training and extent to which they have received training.

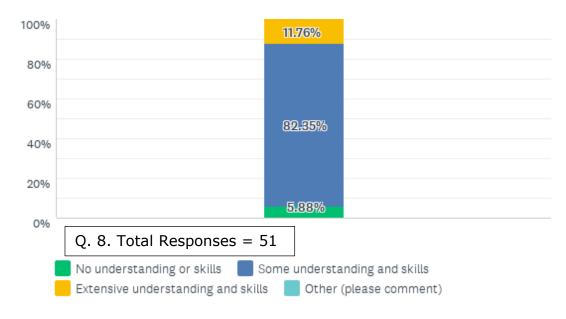
• <u>Question 4</u> asked how respondents would rate their knowledge of types of mental illness (e.g., schizophrenia, bipolar disorder, etc.). Responses are shown below.



The two respondents who answered question 4 with "Other" provided comments explaining how their prior experience with seniors and vulnerable populations provided them with substantial knowledge.

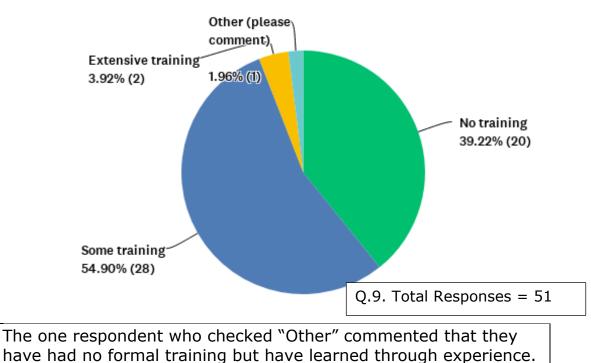
(1) My prior experience before working with seniors was working with disabled clients seeking Social Security/SSI Disability benefits and (2) I have a good bit of experiential knowledge, having practiced a lot in substantive areas related to health and with vulnerable populations.

 <u>Question 8</u> asked about respondents' understanding of common manifestations/symptoms (e.g., hallucinations, delusions, random & warped connections in speech patterns) of mental illness and skills in addressing their impact on representation. Responses are illustrated in the chart below:

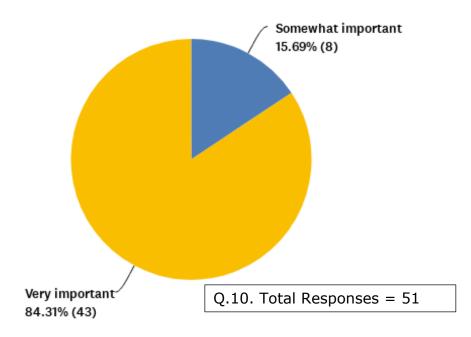


• <u>Question 9</u> asked whether respondents have received training on common manifestations/symptoms of mental illness. Responses

are shown below:



 <u>Question 10</u> asked how important respondents believe training is on common manifestations/symptoms of mental illness; none (0.00%) responded "not important." Responses are illustrated in the graph below.

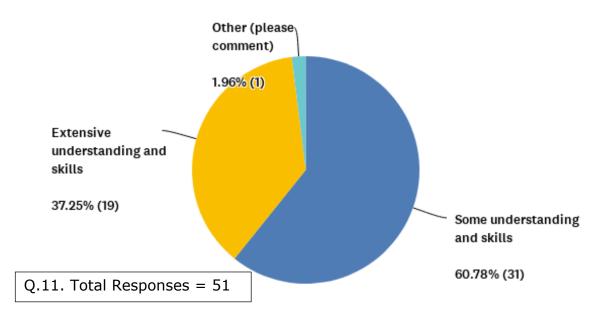


Group 5. Responses to Questions 11-19 which asked how they would rate their knowledge and skills in in a variety of aspects of working with persons with mental illness, including skills in

- Communications;
- ✓ Interpersonal Interactions; and
- ✓ **Accommodations** that may be needed.

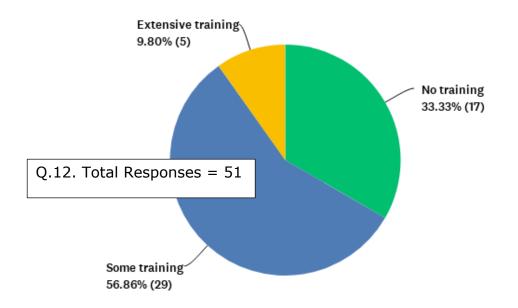
They were further asked if they had received training in these areas and about the importance of training on these various aspects.

• Question 11 asked how they rate their knowledge and skills in **communicating** with persons with mental illness (e.g., listen carefully and actively, affirm that you hear and understand them; don't condescend or be antagonistic or confrontational; avoid legalese, etc.). Responses are shown below.

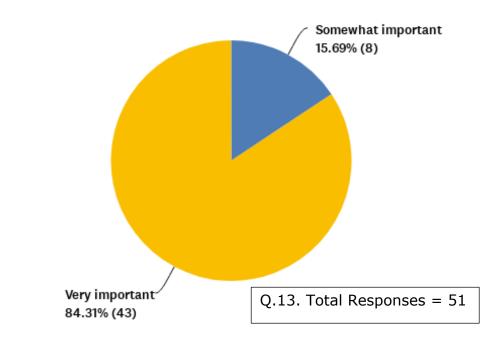


The one respondent who checked "Other" for question 11 explained they think there is a level between 'some' and 'extensive', and they believe they have ample understanding and skills and believe we should do 'all of the above' with all clients, not just those with mental health issues.

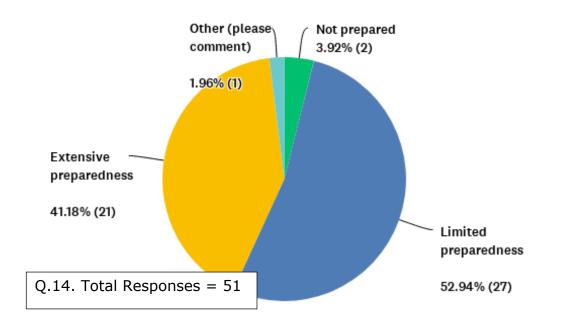
• <u>Question 12</u> asked if respondents have received any training on **communication** skills. Responses are illustrated below.



 <u>Question 13</u> asked how important respondents believe training on communication is. No one (0%) said that it was "not important." Responses are indicated below.

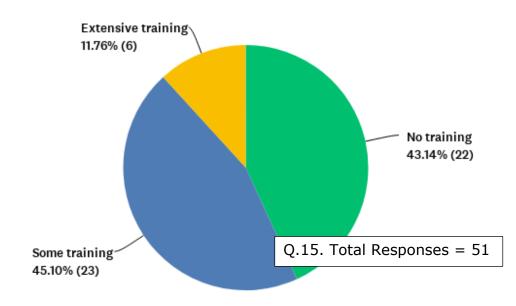


• <u>Question 14</u> asked respondents how they would rate their knowledge of, and skills in **interpersonal interactions** with clients with mental illness (e.g., knowing if and when to touch the person, respect their personal space, downplay the power disparity, etc.). Responses are shown in the chart below.

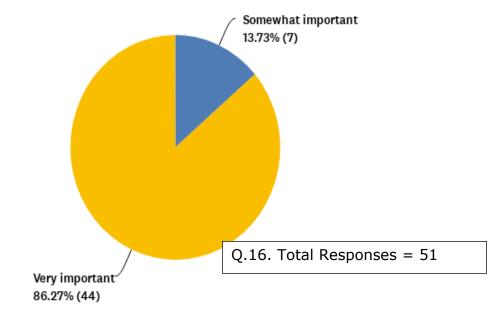


The one respondent who checked "Other" for Question 14 commented they had "sufficient preparedness".

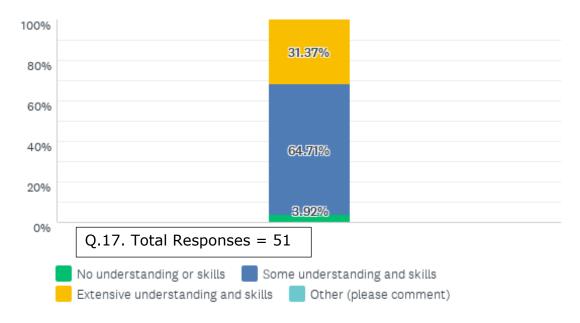
 <u>Question 15</u> asked if respondents had received training on interpersonal interactions with persons with mental illness. Responses are detailed in the chart below.



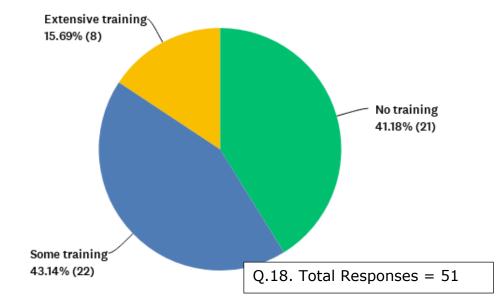
• <u>Question 16</u> asked how important respondents believe training **on interpersonal interactions** is for IIIB and other civil legal services attorneys. No one (0%) said they believe training is "not important." The responses are shown below.



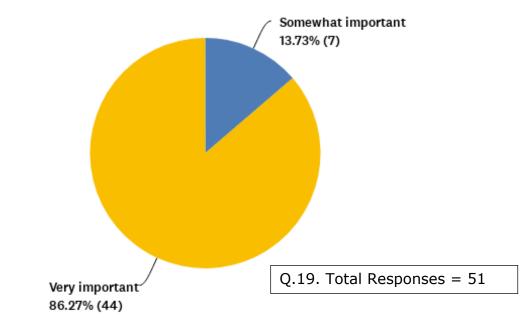
 <u>Question 17</u> asked how respondents would rate their knowledge and awareness about **accommodations** that may be needed to meet needs of older persons with mental illness (e.g., timing and scheduling of meetings to fit the client's needs; taking responsibility for client being upset; awareness of sensory stimuli and effect on client, etc.). Responses are illustrated in the chart below.



• <u>Question 18</u>. The 51 responses to Q.18 regarding whether they have received training on **accommodations** for working effectively with persons with mental illness, are shown below.

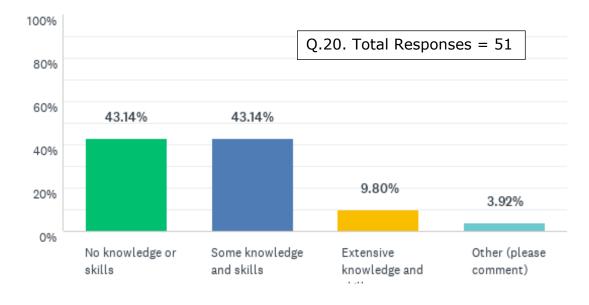


 <u>Question 19</u> asked how important respondents believe training is on **accommodations** for working effectively with older persons with mental illness. No one (0%) responded "not important." Responses are shown in the chart below.



Group 6. Responses to Questions 20-22 regarding knowledge of Psychiatric Advance Directives, skills in drafting them and importance of training.

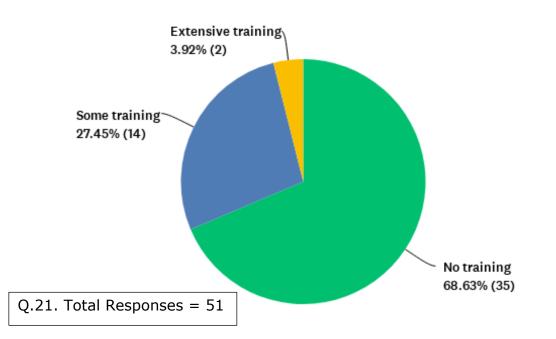
• <u>Question 20</u> asked how respondents rate their knowledge of psychiatric advance directives and their ability to draft them. Responses are shown in the bar graph below



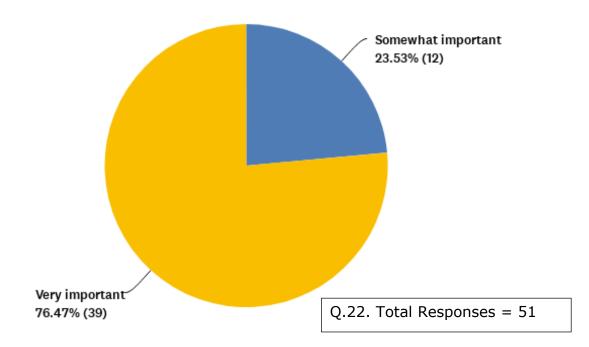
There were 2 comments made by the respondents who answered "Other" to question 20.

1. Have some knowledge but no skills, and 2. Extensive training & experience with durable powers for healthcare, which can include psychiatric treatment though I am aware that the standard forms do not directly address the heightened protections afforded persons suffering mental health issues per Georgia law.

• <u>Question 21</u> asked whether respondents have received training on psychiatric advance directives and on drafting them. Responses are shown in the chart below.

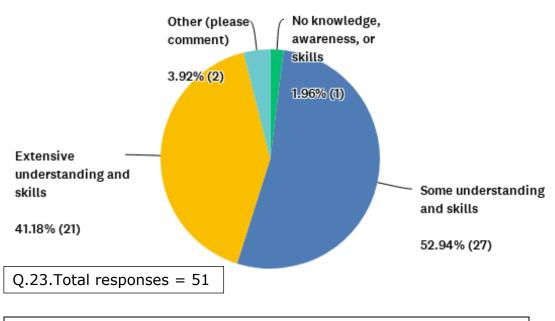


 <u>Question 22</u> asked how important respondents believe training is on psychiatric advance directives and drafting them for elders. None (0%) answered "not important." Responses are shown below.





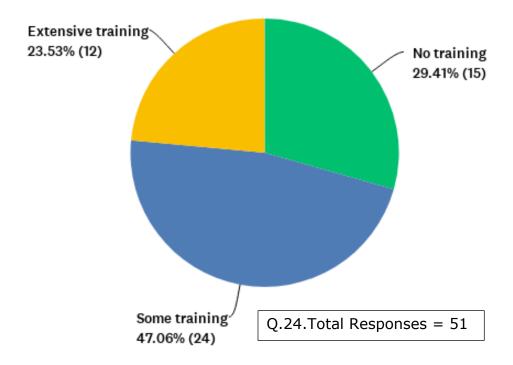
• <u>Question 23</u> asked how respondents would rate their knowledge, awareness and skills in dealing with ethical issues in working with older persons with mental illness. Responses are detailed below.



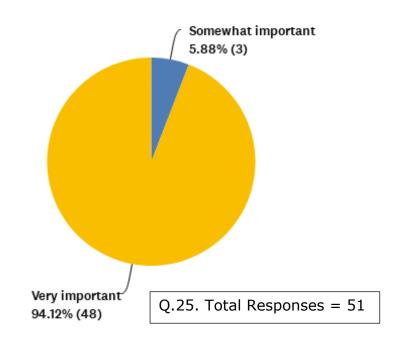
Two respondents checked "Other" and each provided a comment.1. I was a member of my District Ethics Committee. 2. I have

provided some training on this for other attorneys who work with seniors and other persons suffering mental health conditions.

• <u>Question 24</u> asked respondents whether they have received training on ethical issues in working effectively with persons with mental illness. Responses are shown below.

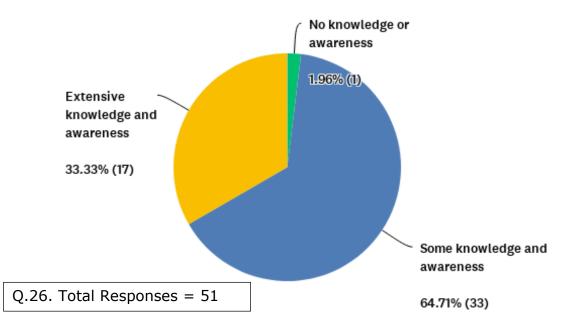


• <u>Question 25</u> asked respondents how important they believe training on ethical issues is for working effectively with persons with mental illness. No one (0%) answered "not important." The responses are illustrated below.



Group 8. Responses to Questions 26-27 regarding knowledge and awareness of **community resources** that could be helpful when working with persons with mental illness.

• <u>Question 26</u> asked how respondents would rate their knowledge and awareness of other resources in the community that could assist in representing older persons with mental illness. Responses are shown below.



• <u>Question 27</u> asked those who checked "some" or "extensive" knowledge and awareness of other community resources to please provide examples of other resources in the community that could assist in representing older persons with mental illness.

Of the 38 total who responded to this question, ALL provided at least one example that was more or less specific (e.g., Crisis Center, and other nonprofit agencies and care providers). However, the vast majority provided a number of examples including national, state and local resources. One respondent provided a very extensive list of specific resources that ranged from Eastside Psychiatric Hospital (an inpatient mental health treatment center) to the Kearney Center which provides meals, emergency temporary shelter/daytime services and medical assistance connections to community resources. (*Please see Appendix 8 [pgs. 85-87] for responses to Survey Question 27.*) **VIII.** Responses to Question 28 (Group 9), Final open-ended question asking for any other comments.

The final question of the survey asked respondents to share any other experience and/or comments they may have about older persons with mental illness and representing them. Twenty-five (25) persons responded to this request, **providing important and insightful comments that will be valuable in guiding future work on this critical issue.** (*Please see Appendix 9 [pgs. 88-90] for responses to survey Question 28.*)

Below are just a few examples:

From comment #1: I have many family members (living and no longer living) who have mental illness. I have learned a lot being around them and have also educated myself about their varying needs . . . They are very special people and have many obstacles to overcome on a daily basis . . . The more you educate yourself about them and their mental health needs, the more knowledge you will have to effectively communicate with them and better assist them with their needs.

From comment #9: We take our ethical obligations to all seniors very seriously. When we believe there are mental health issues we reach out to the Office on Aging and other partners for assistance. The last thing we want to do is to create any additional stress.

From comment #13: It can be very challenging especially during the pandemic but the clients need us and it is well worth helping them.

From comment #21: I think that often times older folks with mental illness are confused with folks who suffer from dementia or Alzheimer's. We need to be more aware that seniors may have had mental illness issues their entire lives and that it is not a new condition associated with aging.

IX. Unsolicited Observation from a State Legal Services Developer

As noted above, in addition to the numerous comments supplied by legal providers responding to the survey, an unanticipated, but welcome result was that a number of state legal services developers responded to our request for their assistance, indicating how important they think the project is. Thus, we **conclude this section** of the report with a quote from one state developer <u>expressing gratitude</u> for our having taken on this <u>critically</u> <u>important project and taking a first step</u> to gather baseline information.

Thank you for including Hawai'i in your project. Just sent out your request to our legal providers.

Sounds like a great project. If you're able to share I'd be very interested in the outcome of the survey. Mental health within the older population has been a concern that continues to be brought up in the aging network, but little has been done around it (I could be wrong but as far as I know). Working with the mental health community has/is on my future to do list and information on what other states do/have done and what is still needed would be valuable in helping to shape how that might look for Hawai'i in the future.

PART FOUR: TRAINING VIDEO ON COMMUNICATING WITH PEOPLE WITH SERIOUS MENTAL ILLNESS

I. Introduction

The training video on *Communicating with People with Serious Mental Illness* was an unexpected, but very important, part of our project. It was conducted for us by Laurie Hallmark, a legal services attorney for Texas RioGrande Legal Aid. Her practice is focused on helping clients with mental illness. She regularly conducts training for other advocates on "Communicating with People with Serious Mental Illness," and is an expert on psychiatric advance directives.

Even though Laurie Hallmark was on our list of potential key informants, it was through one of our research team member's family's connection to Ms. Hallmark that we developed a relationship that allowed us to work even more closely with her. Through a series of fortuitous events, one of our team was able to meet with Ms. Hallmark in Texas and explain our project in person. She was enthusiastic from the moment she heard about the project and was on board with helping us as much as she could. This auspicious beginning led to two in-depth key informant conversations between the research team and Ms. Hallmark and to the project gaining access to training that Ms. Hallmark regularly conducts with staff in Texas on the issues we were pursuing.

During the course of our two key informant interviews with Ms. Hallmark, she referred to this training and graciously offered to conduct it for us. She further agreed to allow us to record it and to use the training as part of our study and to copy/disseminate it via flash drives. (The recording occurred virtually in March 2020). Embedded in Ms. Hallmark's training is a YouTube video, and we also gained permission from the producers of that video to use it. We mailed copies of the flash drives with the presentation:

- to legal services developers, their legal services providers and the state long-term care ombudsmen in those states that participated in the research survey;
- to the legal services developer of the remaining states and territories;
- to key stakeholders who provided assistance to us as we were preparing for our research; and
- to others we believed might benefit from hearing about our research, such as the Administration for Community Living (ACL), the Substance Abuse and Mental Health Services Administration (SAMHSA), Advancing States, and the National Association of Area Agencies on

Aging (N4A) in hopes that they might pursue additional work in this area.

In total, we distributed 231 copies of the training throughout the OAA legal services, aging and advocacy network. (*See Appendix 10 [pg. 91] for information on how to access the communications video*.)

II. Relationship to the Study

In addition to its educational value, the information in this training influenced the design of our survey to Older Americans Act legal providers. Because of it, we were able to identify, define and ask survey questions about the specific kinds of knowledge and training needed to provide quality representation to people with mental illness. Thanks in large part to the knowledge we gained from the training, the survey examined current knowledge, previous training and the value of training for the following specific topics:

- manifestations and symptoms of mental illness;
- skills in communication;
- skills in interpersonal interactions;
- accommodations for people with mental illness;
- psychiatric advance directives; and,
- ethical issues.

We also extrapolated information from the Hallmark presentation to provide examples of each of the specific kinds of knowledge presented by the survey.

While being serendipitous, Laurie Hallmark's participation and gracious willingness to share her training will be of unexpected benefit to the field. We cannot emphasize its value enough. Overall, it added to the knowledge of the researchers and strengthened the outcome in terms of tools that the project was able to provide.

PART FIVE. RECOMMENDATIONS & NEXT STEPS

I. Recommendations

As a first step toward a civil legal services system better prepared to address the needs of older clients with mental illness, this project recommends the following actions.

A. Share Project Findings.

To increase awareness of the issue of older persons with mental illness and to focus more attention on preparing the civil legal services community, particularly the Older Americans Act legal community to represent this population in the best way possible, widespread dissemination is essential. Thus, the information and results of this project will be shared with the Administration for Community Living (ACL), the Substance Abuse and Mental Health Services Administration (SAMHSA), Advancing States, and the National Association of Area Agencies on Aging (N4A) in hopes that they will provide funding for continued efforts in the area. The final project report and the training video have already been shared with the aging and legal networks as described in Part Four of the report. Further, the project report will be available on The Center for Social Gerontology's website and its availability will be advertised to State Units on Aging, Legal Services Developers, State Long Term Care Ombudsmen and others in the aging network. Without widespread dissemination of project results and recommendations, there is the risk that:

- The needs of older clients with mental illness could inadvertently be overshadowed by Alzheimer's Disease and related dementia diagnoses;
- This population will be underserved due to lack of training and expertise on communication and interpersonal interaction skills as well as best practices for accommodations; and,
- This extremely vulnerable population could be at greater risk for abuse and exploitation. "Psychiatric illness is an important cause of vulnerability to abuse, especially when it is comorbid with other risk factors, such as physical frailty, sensory impairment, social isolation, and physical dependency⁷."

⁷ Cooper C, Livingston G. Mental health/psychiatric issues in elder abuse and neglect. Clin Geriatr Med. 2014 Nov;30(4):839-50. doi: 10.1016/j.cger.2014.08.011. Epub 2014 Sep 2. PMID: 25439645

B. Expand Legal Ethics Discussions and Training to include more examination and discussion of scenarios about older clients with mental illnesses.

- Often in trainings and conferences within the aging network, it is common for these discussions to weigh heavily on older clients with diminished capacity due to Alzheimer's Disease and related dementia. Seldom, if ever, are the issues of mental illness raised or are experts in the area of mental illness added to the discussion of ethics or substantively included.
- We are inadequately preparing our legal providers if we fail to take every opportunity to assure that guidance is provided to enable them to provide representation to clients with mental illness in cases that are unrelated to a client's mental illness. We do a disservice to the provider and fail to provide the best service to older clients with mental illness.

C. Involve Experts and Researchers from Educational Institutions, Especially Those with Medical or Psychology

Backgrounds, in the development of resources and the conduct of training.

From discussions with our key informants from universities, we gained an enormous body of knowledge about the clinical aspects of mental illness. The attorneys we spoke with were quick to preface many comments with the caveat that they were not doctors or psychologists. Including doctors, psychiatrists and psychologists with an academic perspective in the discussion of how best to prepare attorneys is critical to a comprehensive approach to training and the development of resources.

D. Broaden Content and Scope of Training for Older Americans

Act Legal Providers and Civil Legal Services Attorneys which has always been critical to them gaining substantive knowledge and obtaining skills needed to zealously represent their clients.

- Representing clients with mental illness requires some substantive knowledge and skill sets outside the areas that most attorneys acquire through the normal continuing legal education courses.
 - It is necessary for at least some baseline **focused training** to ensure all Older Americans Act legal services attorneys (and other civil legal services attorneys) have enough knowledge of mental illness to recognize:
 - ★ That it is different from dementia;
 - ★ How to effectively problem solve/accommodate the older person from a person-centered approach; and,

- ★ A diagnosis of mental illness does not automatically preclude representation.
- Making appropriate accommodations, and interacting and communicating effectively with a person with mental illness are likely to be new skills not used with other clients:
 - Attorneys must learn how to modify effectively their own behaviors and reactions so as not to lose their client's trust;
 - It is <u>incumbent upon the attorney</u> to recognize if and when to push forward, when to pause and reset, and when to not give up. Without this recognition the attorney risks losing the opportunity to serve the client;
 - ★ Effective training makes that possible;
 - The attorney must spend more time preparing the client for the environment and procedures of any hearings or meetings that are needed to accomplish the client's goals; and,
 - ★ Patience can be learned behavior for the attorney and has mutual benefits.

E. Educate about Psychiatric Advance Directives and Their

Incorporation into States' Health Care Directives.

Many states' laws do not allow for stand-alone Psychiatric Advance Directives (PADs). However, every state makes provisions for some form of health care directive or advance directive for health care. There are gradations of mental illness and depending upon the diagnosis, there are variations in onset and causations. For persons who have the ability and opportunity to voice preferences about treatment, lifestyle, medication side-effects, long-term treatment effects, etc. they may want to express those in an advance directive. These may not always be considered in drafting typical health care advance directives.

- Without proper training on Psychiatric Advance Directives, Older Americans Act legal providers and civil legal services attorneys will not know what PADs are able to do.
- Older clients with mental illness will be deprived of a voice to express what their preferences are about these important life choices and what impact they can have on the client's life.
- Most OAA legal providers are very familiar with health care advance directives:
 - Knowing how to tailor these to incorporate specific life choices for clients with mental illnesses can be life-changing for the older client; and,
 - Older clients with a long history of mental illness will be able to better direct their legal provider in how past treatments have

affected them and at what costs they wish to be treated in the future, i.e., what they're willing to sacrifice.

• Proper language in a health care directive that speaks of psychiatric advance direction can be the <u>bridge</u> that an older client with mental illness needs to protect their way of life for the future.

II. Next Steps

Where to go from here? Each of these topics is just the beginning. We have had a year to start looking into this and feel like we have just begun to scratch the surface. The more we learned, the more we realized we did not know. The more questions we asked and found answers to, the more questions we discovered those questions generated or led to as a result. Here are some additional areas for inquiry:

- Should there be a specialist trained in each legal services program or at least in the state as a "go to" resource attorney?
 - This would be in addition to every attorney's training.
- Should the courts receive training as well?
 - This is not unlike the questions and concerns that the aging and guardianship advocates were asking around Alzheimer's Disease and dementia-related issues not so long ago.
- Who else in the Aging Network referral chain should be properly trained to make sure that the older client with mental illness has no barriers getting to the legal provider?
 - How do we make sure the barriers along the way are lowered?
 - Where does the communication training start?
 - What does it look like?
- While this study did not have the resources to examine psychiatric advance directive laws in each state, we know that stand-alone psychiatric advance directive laws do not exist in every state. Further study of this issue is merited.
- In addition, just as with all advance directives, further study and education is needed to work with medical providers and mental health providers so that they are fully educated about psychiatric advance directives and understand their duty to follow them when they are used.

III. Ultimate Goal

- If Ms. Smith has a housing, social security, consumer, mortgage, exploitation, Medicare or SNAP issue, she should be able to go to a legal provider and seek assistance notwithstanding that she also has a diagnosis of bipolar affective disorder, schizophrenia or some other mental illness. Regardless, of her mental illness diagnosis, and all of its complications, <u>Ms. Smith's legal problem</u> <u>still exists</u> for which she needs legal assistance.
- We have to make sure that our legal providers are prepared to work with Ms. Smith despite her mental illness and are able to represent her with her legal problem just as they would any other client, if that is at all possible.

IV. Conclusion

From discussions with key informants and from comments of survey respondents, it is clear that working with persons with mental illness can be challenging. However, it is also very clear that working with clients with mental illness is some of the most rewarding work that a legal provider can undertake. It is our hope that the preliminary work done here will be enough to encourage others to pick up where this study leaves off and to move this work forward. If even one recommendation or suggested next step is pursued and advanced to the next level this project will have been a success. **There is more work to be done!**

APPENDICES

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Appendix 1: One-Page Summary of the Project

A Project to Assess What Is Needed to Prepare Older Americans Act Legal Services to Represent Older Clients with Mental Illness

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Funded by:

The Borchard Foundation Center on Law and Aging. (See Borchard Foundation's website for more information. <u>https://borchardcla.org/who-we-are/mission-and-history</u>)

Overview of the Project: This project takes an important first step toward achieving a workforce of Older Americans Act (OAA) legal providers (and other civil legal services) prepared to provide effective legal representation to elderly clients with mental illness.

Need for the Project: Title IIIB of the OAA provides for the provision of civil legal services to America's most vulnerable older persons. While substantial work has been done to develop training and resources for legal services providers on how to handle capacity and ethics issues related to the representation of clients with Alzheimer's and related dementias, there has been little focus on preparing them to provide representation to older Americans with mental illness.

It is estimated that 20% of people 55 years or older experience some type of mental health concern, and mental health issues are often implicated in the suicide of people 55 and over. Recent data from the Substance Abuse and Mental Health Services Administration (SAMHSA) for the state of Georgia indicates increasing numbers of elderly persons are being served by Georgia's state mental health system. Despite these and other data, a preliminary survey by project researchers of internet resources and knowledgeable agencies indicates a dearth of relevant training and resources for civil legal providers representing older clients with mental illness. Legal providers have expressed to researchers an eagerness for training/resources on how best to represent elderly clients with mental health issues, including on safety issues, enhancing interviewing skills, identifying that a client has a mental illness or is exhibiting symptoms, how mental illness might affect a client's ability to receive instructions or participate in their case, issues related to interacting with and gaining the trust of a client, working past the stigma of mental illness and the attorney's personal reaction to a client with mental illness, and navigating other challenges specific to working with clients with mental illness.

Methodology: To identify how best to move forward to prepare legal services programs to handle the representation of elders with mental illness, the project will identify existing resources, as well as gaps in these resources by: (1) surveying OAA IIIB legal providers; (2) seeking advice/input of key experts in geriatric mental health and legal representation of clients with mental illness to gain their perspective on what legal providers need to know and understand to best serve this population; and (3) analyzing the information we glean from the experts and from our survey, to create written recommendations for next steps for developing needed training and resource support materials.

Appendix 2: Sample Letter to Key Informants/Experts Requesting Assistance



September 12, 2019

Laurie Hallmark, J.D. Managing Attorney Texas RioGrande Legal Aid 331A N. Washington St. Beeville, TX 87102

> RE: Request for Assistance on Delivery of Legal Services to Elders with Mental Illness

Dear Ms. Hallmark:

The purpose of this letter is to ask if you would be willing to serve as an expert/key informant on a *groundbreaking*, one-year project on provision of civil legal services to *older persons with mental illness*, particularly services provided under the Older Americans Act (OAA). This project takes an *important first step* toward the long-term goal of achieving a workforce of OAA legal providers (and other providers of civil legal services) with the necessary skills, awareness and support to provide effective and successful representation of these clients.

First, allow us to introduce ourselves. We are a team of three researchers collaborating on this project:

<u>Penelope Hommel</u>, Director, The Center for Social Gerontology, Ann Arbor, Michigan <u>Lauren Lisi</u>, Consulting Attorney, The Center for Social Gerontology, Ann Arbor, Michigan, and <u>Natalie Thomas</u>, Legal Services Developer, Atlanta, Georgia

Together, we have over 90 years of experience working to ensure the rights of older persons, focusing specifically on safeguarding older Americans' access to the best possible legal assistance when faced with serious legal problems. The OAA establishes legal services as a priority service and specifies that the limited services be targeted to the most needy and that they focus on the most critical legal issues threatening elders' health and safety. The three of us have worked for decades to ensure that such targeting is reality.

However, there has been an important gap in preparing providers to target one particular group –older persons with mental illness. While substantial work has been done to develop resources and training to assist in targeting older persons with Alzheimer's and related dementias (e.g., on capacity and ethics), almost nothing has been done to prepare them *to represent older persons with mental illness* – even as the numbers/percentages of elders with mental health issues are increasing. Recently, OAA legal providers, themselves, have expressed a real need for training and resources to better serve this population, including on such things as:

- safety issues;
- enhancing interviewing skills;
- identifying that a client has a mental illness or is exhibiting symptoms;
- how mental illness might affect a client's ability to receive instructions or participate in their case;
- issues related to interacting with and gaining a client's trust.

In response, we were able to obtain a small grant from the Borchard Foundation Center on Law and Aging to begin to *move into this uncharted territory*. The project we designed has three components (see attached Project Description).

The second component is most important — that is, to solicit *advice of experts/key informants in the areas of geriatric mental health and/or legal representation of persons with mental illness to gain their perspective on what legal providers need to know and understand to best serve older Americans with mental illness. This is where our request to you comes in.* We believe that your lengthy history of working with mental health issues and your background in civil legal services will be invaluable to us as we identify resources and best practices to enhance the skills of legal services providers representing older persons with mental illness. We first became aware of your expertise in this area through Alison Lisi, a TRLA attorney in Brownsville who has attended one of your trainings and who happens to be the daughter of Lauren Lisi, a researcher on this project. We are particularly interested in your focus on self-determination based holistic civil legal services and work to restore rights of those placed under guardianship, as well as your work with psychiatric advance directives, and with the Saks Institute for Mental Health Law, Policy and Ethics. The experience you have had in developing materials, training and tool kits for working with attorneys who represent clients with mental illness is exactly the kind of resource that we are hoping to develop and strengthen in the OAA legal provider and greater civil legal services community.

If you agree to help us, we propose to work with you through telephone interviews. While we will have questions we want to ask all key informants, we anticipate that you and others will direct us to areas of inquiry we had not considered. We are very flexible in the length and timing of interviews and anticipate working around your time constraints and schedule.

We will contact you in the first week of October by email to see if you are willing and able to assist and, if so, to schedule an initial phone call. Please also feel free to call and/or email us with questions or concerns in the interim.

Please see the attached one-page summary of the proposed project in which you will find ---

- contact information for the three researchers, and
- a link that provides a description of the Borchard Foundation and Borchard Foundation Center on Law and Aging.

We hope that you have the time and the interest to participate in this project.

Respectfully yours,

Penelope Hommel	Lauren Lisi	Natalie Thomas
phommel@tcsg.org	llisi@tcsg.org	natalie.thomas@dhs.ga.gov

Encl

Appendix 3: Information on Four Key Informants/Experts

Laurie Hallmark, Esq. Special Project Director Texas RioGrande Legal Aid San Antonio, TX

Providing self-determination based, holistic civil legal services and advocacy to assist individuals with serious mental illness to access the supports and services they want and need in order to live in the manner they choose, integrated into the community. Promoting the use of specialized psychiatric advance directives to increase autonomy for the person with serious mental illness and accountability for the services they receive.

Marshall Kapp, J.D., M.P.H. Professor Emeritus Florida State University College of Medicine Tallahassee, FL

Taught on legal and ethical aspects of health care; Professor in College of Medicine Department of Geriatrics, *Professor of Medicine and Law in College of Law*

Victor Molinari, PhD, Professor, School of Aging Studies, Behavioral and Community Sciences, University of South Florida, Tampa, FL

Professor and Researcher – major research interests include mental health outcomes in long-term care sites serious mental illness in nursing homes, professional issues in geropsychology and personality disorder in older adults.

Ann Renaud, Esq. Ramp, Renaud & Hlavenka, LLC East Brunswick, NJ

The Mental Health Advocate for her firm -with over 30 years' experience. Recognizes that people with mental health issues often need more than legal representation when they are in trouble. Because of their problems, these individuals can be ignored by schools, businesses and governmental agencies. She acts as their intermediary.

Appendix 4: Questionnaire to Guide Interviews/Conversations with Key Informants/Experts

INTRODUCTION AND QUESTIONS FOR EXPERTS/KEY INFORMANTS FOR -

PROJECT TO ASSESS WHAT IS NEEDED TO PREPARE OLDER AMERICANS ACT LEGAL SERVICES PROVIDERS TO REPRESENT OLDER CLIENTS WITH MENTAL ILLNESS

INTRODUCTION

Review of Need for, and Purpose of, the Project

<u>Need for the Project</u>: The Older Americans Act (OAA) establishes civil legal services as a priority service and specifies that the limited services be targeted to the most needy/vulnerable elders and that they focus on the most critical legal issues affecting them. But there has been an important gap in preparing legal providers to target one particular group—older persons with mental illness -- even as numbers/percentages of elders with mental health issues are increasing.

<u>The Purpose of the Project is to take an important first step toward the long-</u> *term goal of training a workforce* of OAA legal providers (and other civil legal service providers) with the necessary skills, awareness and support to provide effective and successful representation of older clients with mental illness. *The immediate goal is to produce a written document that recommends specific components and resources for such training.*

Why the Expertise of Key informants is Needed

While the three researchers (Penny Hommel, Lauren Lisi and Natalie Thomas) have considerable expertise in the delivery of legal services to many of the most needy older Americans, we have little to no experience with mental illness. To achieve the project's purpose, we look to you, the experts, to guide us on what training, resources, and understanding are needed to enable legal services attorneys to provide effective services to older clients with mental illness, and to do so with sensitivity and the skills needed to communicate effectively and to build trusting relationships, as well as to assist us in asking the right questions.

Our Special "Ask" of the Experts

An overriding goal throughout the work on this project and as we discuss the issues with you, our experts, is to be respectful of persons with mental illness and to make sure that project activities are person-centered and that

they promote inclusivity, empathy and respect for all communities. It is our hope that you will bring to our attention any comments, questions, or project activities that do not comport with this goal.

Disclaimer. Each of our key informants brings a unique perspective and expertise to the project. Not all questions we are exploring will fall within the particular expertise of any one informant. Please do not feel you need to comment on, or respond to, questions that fall outside your particular area(s) of expertise.

Mental Illness vs. Alzheimer's Disease and Related Dementias.

Please note that for purposes of this project, we do not want to include Alzheimer's Disease and related dementias under the term "mental illness." This is because substantial work has been done to develop resources for legal services providers on how to handle capacity, ethics issues and others issues related to representation of clients with Alzheimer's and related dementias. We want to focus this project on unexplored areas relating specifically to representation of elders with mental illness.

QUESTIONS FOR KEY INFORMANTS

Prefatory Notes:

* Unless otherwise stated, "legal provider" means an Older Americans Act (OAA) legal provider for the elderly, and "client" means older client or older person

* In general, clients served by OAA legal providers would not be represented because of a specific mental health issue. Rather, they might have a civil legal issue, like a housing, public benefits, or health care access issue. In most cases mental health problems would be tangential or unrelated to the specific legal issue that brought the client to the legal provider's office.

Training Specific to Mental Illness: What is Mental Illness? What Level of Understanding of Mental Illness Do Legal Providers Need?

- As we work on this groundbreaking project, and keeping in mind that we do not want to address Alzheimer's Disease or related dementias, <u>how would you define mental illness</u> particularly as it pertains to older persons, for an attorney or intake worker with little or no knowledge of mental illness?
- 2. What <u>level of understanding of the characteristics of various mental</u> <u>illnesses is required</u> for legal providers to deliver effective services to

clients with a mental illness? What training is required so that they can understand and can recognize signs and symptoms of mental illness in a client's behavior, including a <u>client's ability to receive</u> <u>instructions or participate</u> in their case? Should this training include description/discussion of other circumstances that may mimic or exacerbate mental illness, e.g., PTSD or trauma?

- 3. What might be the <u>consequences for the client if an attorney is not</u> <u>sufficiently educated</u> about mental illness and its effects on the client's ability to participate in their case? For example, how might this affect discussions between the client and legal provider, the client's ability to make informed decisions, or the client's ability to participate in an administrative hearing or court forum?
- 4. What do you see as <u>the greatest challenge for legal providers</u> who represent clients with mental illness?

Training Specific to Mental Illness and the Elderly: What Do Legal Providers Need To Know About The Specific Challenges They May Encounter When Working With Older Clients With Mental Illness?

- 5. Given that the focus of this project is on the delivery of legal services to **older individuals** with mental illness, <u>do older persons with</u> <u>mental illness have specific challenges</u> not generally experienced by younger adults with mental illness? If you feel there are specific challenges more likely to be faced by older adults with mental illness, could you elaborate?
- 6. In cases of <u>late-onset</u> mental illness, are there important differences/challenges that legal providers should be prepared to address? If yes, please elaborate a bit.
- 7. Is <u>safety an issue</u> that should be addressed in training legal providers to represent older persons with mental illness?

Training On Effective Communication And Gaining A Client's Trust:

What Can The Legal Provider Do To Ensure That Their Relationship With The Client Is As Supportive and Effective As Possible?

- 8. What, if anything different, do legal providers need to do to <u>enhance</u> <u>their interviewing skills</u> to prepare for clients with a mental illness?
- 9. What specific skills, knowledge or training can help to <u>foster mutual</u> <u>trust</u> between the attorney and the client with a mental illness?

Training to Meet the Client's Needs: What Accommodations Should Be Considered? How Might The Legal Provider Use Community Resources And Services To Meet The Client's Full Range Of Needs?

- 10. What, if any, <u>adaptations might be required</u> in a legal provider's office/intake site to accommodate the needs of a client with a mental illness? Similarly, what accommodations might need to be requested of the administrative forum or court to meet a client's specific needs?
- 11. What <u>community services or resources</u> should legal providers be knowledgeable about when representing clients with mental illness? When is it appropriate to refer a client to supportive services in the community?

Training on Ethical Issues: What Are The Boundaries To The Legal Providers Ability To Assist The Client?

- 12. Are there any circumstances <u>when the client with mental illness</u> <u>cannot be represented because of the severity of their mental illness</u>? What should a legal provider do in that instance?
- 13. When, if ever, should a legal provider <u>push a client with a mental</u> <u>illness to seek counseling or treatment</u> for a mental illness or a suspected mental illness?
- 14. Are there <u>different ethical considerations</u> when working with clients with mental illness than with clients with dementia? Are the precautions for attorneys the same? What are those ethical considerations, if different?

Training On Psychiatric Advance Directives: What Should Legal Providers Know about Psychiatric Advance Directives? Are There Other Helpful Tools For Assisting Clients With Mental Illness?

- 15. Can you describe how and when a legal provider might use <u>psychiatric</u> <u>advance directives</u> for clients with mental illness?
- 16. If you assist clients in using psychiatric advance directives, <u>how often</u> <u>are these tools used</u> in your practice?
- 17. <u>Do you recommend</u> that all legal providers be trained on psychiatric advance directives?
- 18. <u>Are there other kinds of documents or legal tools</u>, besides psychiatric advance directives, that are particularly useful when working with clients with mental illness?

Final Wrap up Questions/Requests:

- 19. What Else? What do we need to know that we don't know to ask?
- 20. **Materials to Share?** Do you have or can you recommend any training materials, curricula, articles etc. that you believe would be helpful and that you would be willing to share with us?
- 21. **Follow up Contact?** May we contact you again if further information is needed?

Appendix 5: Sample Letter Requesting Assistance of Select Developers in Disseminating the Survey to Providers



To: From: Penny Hommel Subject: Request for your assistance Date:

Dear,

We hope you are doing well in these unsettling times.

I am sending this request for your assistance along with Natalie Thomas, Georgia Developer, and Laurie Lisi of The Center for Social Gerontology (TCSG). We have received a small grant from Borchard Foundation to work on an exciting, groundbreaking project. (Please see attached for a one-page summary of the project.) The project purpose is to gather first-ever information on:

The Experience, Knowledge and Preparedness of OAA Title IIIB Legal Services Providers to Represent Older Persons with Mental Illness.

While older persons with mental illness is clearly an important target group under the Older Americans Act, little attention has been paid them in the past. And almost nothing has been done to prepare OAA legal providers (and other providers of civil legal services) with the necessary skills, awareness and support to provide effective and successful representation of these clients, even as the numbers/percentages of elders with mental health issues are increasing.

Thus a critical piece of the project is to <u>survey Title IIIB legal providers</u> in a number of select states to gather baseline information on the experience; the knowledge and understanding; the challenges; and the training or lack of training of IIIB direct legal providers in working with older persons with mental illness.

<u>Our request to you as developer</u>, is to email the link to the survey, (which includes background information about it) to your IIIB legal providers across the state, asking them to please complete the survey. <u>Below (and also attached as a Word document) is a sample</u> of what your email might say; it includes a link to the survey. <u>Please adapt and personalize it as you wish before sending it on</u> to your providers.

We apologize, but this is time-sensitive, as we are asking providers to respond to the survey by June 1, 2020. Thus we ask that you send your email to your providers ASAP. We will be extremely grateful for your assistance, and thank you in advance for your help.

If you have questions, please feel free to contact any one of us.

Be well and stay safe.

Natalie Thomas, <u>Natalie.Thomas@dhs.ga.gov</u>, Phone: 404-657-5328 Lauren Lisi, <u>llisi@tcsq.org</u> Phone: 248-854-8744

Penny Hommel, phome: 231-599-3412

Sample email to IIIB providers to be adapted/personalized by developer

To: Title IIIB Legal Services Providers

From: Chisorom Okwuosa and Carmen _____

Subject: Please complete survey on Your Preparedness to Represent Older Persons with Mental Illness by **June 1, 2020**

Dear (IIIB legal provider)

Can you please respond to a special request we received from the Georgia Legal Services Developer, Natalie Thomas and Penny Hommel & Laurie Lisi of The Center for Social Gerontology (TCSG).

They have requested that you complete a short survey for a cutting edge project they are undertaking to gather first-ever information on:

"The Experience, Knowledge and Preparedness of OAA Title IIIB Legal Services Providers to Represent Older Persons with Mental Illness.

The survey link below provides more information about the project.

It should take only about 10 minutes to complete. It is time-sensitive and they have set a **deadline of Monday, June 1, 2020**

For the link for more information and to take the survey go to

https://www.surveymonkey.com/r/N673LYW

Natalie, Laurie, and Penny will be most appreciative of your timely response

Thank you,

(developer signature)

Appendix 6: Title IIIB Survey Scenarios

Your client has trusted you enough to have already revealed their mental illness diagnosis and is currently in your office for a meeting or with you at a hearing, and you observe one of the following

- Client becomes extremely agitated and states the belief that they are elsewhere, and they are terrified. When you ask what they mean, they tell you, someone moved them from where they were.
- Your client suddenly does not recognize you. One minute you were having a conversation and now your client accuses you of being from a secret federal agency that has been following him and investigating him and he doesn't trust you.
- The client believes he is scheduled for a doctor's appointment today instead of an appointment with his lawyer and wants to begin removing his clothes to prepare to be examined.

Appendix 7: The Complete IIIB Survey Instrument (Responses Not Included)

Survey on Preparedness of legal services providers to serve elderly persons with Mental Illne

INTRODUCTION

By completing this survey you will help us gather the first of its kind information on the Experience, Knowledge & Preparedness of Legal Services Providers to Represent Older Persons with Mental Illness

Importance of this Survey. The Older Americans Act (OAA), Title IIIB legal assistance program is designed to ensure that the most vulnerable older persons have access to, and are provided, quality civil legal services. While older persons with mental illness in need of legal assistance certainly qualify as a vulnerable population, there has been minimal focus on the awareness and preparedness of IIIB legal providers (and other civil legal service providers) to provide quality representation to this growing population. (Note: The World Health Organization, in a December 2017 fact sheet, estimates that 20% of the world's adults aged 60 and over suffer from a mental disorder.) This survey is an essential first step in compiling information on this issue.

Early Input from Legal Providers is Essential. Results of this survey will be critical to developing initial recommendations regarding what is needed to increase understanding and enhance essential skills, as well as overcome existing gaps that currently limit the ability of OAA legal providers to represent effectively older persons with mental illness. Thus an initial step is to ask you – direct providers of legal services to older persons — for baseline information about such things as: your experience; knowledge and understanding; challenges; and training/lack of training on working with older persons with mental illness

Prefatory Notes:

1. Unless otherwise specified "client" refers only to clients aged 60+

2. Your responses to this survey are very important. Most of the questions can be answered very quickly by checking a box or boxes. A few require open-ended responses. While you don't have to respond to open-ended questions if you don't have time, we urge you to do so and also urge you to insert comments at the end of the close-ended questions as appropriate. Because this survey seeks information about a cutting edge issue, every bit of data will help.

3. There are 28 total questions in this survey. However, the survey is designed to skip questions that are inapplicable to you, in light of your answers to previous questions. The survey will take about 10 minutes to complete.

4. If you don't have time to complete the survey all at once, you can start it and come back and complete it at a later time.

5. Please complete this survey by JUNE 1, 2020.

Working Definition.

We recognize there are a variety of definitions of mental illness. For purposes of this survey, we define mental illness as a mental, behavioral or emotional disorder (excluding developmental and substance use disorders) resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities including work, social, and family life. For survey purposes we are talking about something that rises to a level that it significantly impacts a client's thinking, emotion and behavior, including their ability to be represented legally. This is often categorized as "serious mental illness" and examples include major depressive disorder, schizophrenia and bipolar disorder.

Survey on Preparedness of legal services providers to serve elderly persons with Mental Illne

STRUCTURE OF THE SURVEY.

The questions below are divided into four (4) broad categories, as follows:

I. Questions about any <u>professional experience</u> you have in representing persons with mental illness – either older or younger.

II. Questions about any <u>personal experience</u> you may have with persons with mental illness of any age, as well as any pre-conceptions you may have about such persons.

III. Questions about your <u>knowledge and skills</u> regarding how best to represent/interact with older clients with mental illness, as well as about training/resources you have received or you feel are needed to be able to serve effectively older clients with mental illness.

IV. Final question allowing you to provide us with any <u>additional comments</u> that will add to our understanding.

Survey on Preparedness of legal services providers to serve elderly persons with Mental Illne

Questions about any <u>professional experience</u> you have in representing persons with mental illness.

Note: For question 1 below, assume the following:

Your client has trusted you enough to have already revealed their mental illness diagnosis and is currently in your office for a meeting or with you at a hearing, and you observe one of the following

• Client becomes extremely agitated and states the belief that they are elsewhere, and they are terrified. When you ask what they mean, they tell you, someone moved them from where they were.

· Your client suddenly does not recognize you. One minute you were having a conversation and

wi	The client believes he is scheduled for a doctor's appointment today instead of an appointment h his lawyer and wants to begin removing his clothes to prepare to be examined.
	1. Assuming the scenarios described above, how prepared are you to address your client's needs?
	Not at All
	Somewhat
	Definitely
	Comments:
	2. In your professional experience, how often (if ever) have you had a client of any age that you knew or suspected had a serious mental illness?
	Never that I'm aware of
	Rarely
	Occasionally
	Frequently
	Survey on Preparedness of legal services providers to serve elderly persons with Mental Illne 3. In your professional experience, how often (if ever) have you had an older client (age 60+) that you knew suspected had a serious mental illness?
	Cccasionally
	Occasionally

4. How would you rate your knowledge of types of mental illness? (For example schizophrenia, bipolar disorder, anxiety disorder, depression, delusional disorder, trauma related disorder)

O No knowledge

Some knowledge

Extensive knowledge

Other (please comment)

Survey on Preparedness of legal services providers to serve elderly persons with Mental Illne

II. Questions about any <u>personal experience</u> you may have with persons with mental illness of any age

5. What personal experience, if any, do you have interacting with persons with mental illness, e.g. friends, family, colleagues?

O None

Occasional

Frequent

Other (please comment)

Survey on Preparedness of legal services providers to serve elderly persons with Mental Illne

6. If you have had personal experience, what difference has it made in your attitude or in how you interact with them?

- O Prompted me to learn more about mental illness and its manifestations
- Caused me to have a more positive attitude about persons with mental illness
- Caused me to have a more negative attitude about persons with mental illness
- Caused me to become an Advocate for them/their rights
- Caused me to become a provider of health, social and or support services for them
- Other (please describe)

Survey on Preparedness of legal services providers to serve elderly persons with Mental Illne

7. Given that you have no personal experience interacting with persons with mental illness, do you think you have preconceived ideas about such persons?

- O Yes
- O No
- Other (please comment)

Survey on Preparedness of legal services providers to serve elderly persons with Mental Illne

Questions about <u>your knowledge and skills</u> regarding how best to represent/interact with older clients with mental illness, as well as about training/resources you have received or you feel are needed to be able to serve effectively older clients with mental illness 8. How would you rate your understanding of <u>common manifestations/symptoms of mental illness</u> and your skills in addressing their impact on representation of clients? (For example: hallucinations and delusions, disorganization/scattered thoughts, random & warped connections in speech patterns, backward/circular reasoning)

- No understanding or skills
- Some understanding and skills
- Extensive understanding and skills
- Other (please comment)

9. Have you had training on common manifestations/symptoms of mental illness?

- No training
- Some training
- Extensive training
- Other (please comment)

10. How important do you believe training on common manifestations/symptoms of mental illness is for IIIB and other civil legal services attorneys?

- Not important
- O Somewhat important
- Very important

11. How would you rate your knowledge and skills in <u>communicating with clients with mental illness?</u> (For example: listen carefully and actively check that you understand what they mean and affirm that you hear and understand them; be encouraging; keep calm; be patient and be respectful; make an interview more of a conversation than a formal interview; be careful not to discount their perspective; don't condescend or be antagonistic or confrontational; avoid legalese; and overall remember that language matters-they are persons with mental illness, not the mentally ill.)

- No understanding or skills
- Some understanding and skills
- Extensive understanding and skills
- Other (please comment)

12. Have you had training on communicating with persons with mental illness?

- No training
- Some training
- Extensive training
- Other (please comment)

13. How important do you believe training on communicating with persons with mental illness is for IIIB and other civil legal services attorneys?

Not important

- Somewhat important
- O Very important

14. How would you rate your knowledge of, and skills <u>interacting with clients with mental illness so that they</u> <u>feel comfortable</u>? (For example, know when and if to touch the person; respect their personal space; downplay the power disparity by dressing down; do not meet across a desk but rather have comfortable seating; let the client choose the chair; meet in an informal place such as coffee shop or their home; provide beverages and/or food)

O Not prepared

Limited preparedness

- Extensive preparedness
- Other (please comment)

15. Have you had training on interpersonal interactions with persons with mental illness?

\bigcirc	No	training
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O Some training

- Extensive training
- Other (please comment)

16. How important do you believe training on interpersonal interactions with persons with mental illness is for IIIB and other civil legal services attorneys?

Not important

Somewhat important

Very important

17. How would you rate your knowledge and awareness of <u>accommodations</u> that may be needed to meet the needs of older persons with mental illness? This could include accommodations regarding timing and scheduling of meetings as well as other accommodations. For example:

o Re timing and scheduling: allow client to set the schedule; do not rush the client; reschedule if necessary, making the appointment when client/you will not be rushed; reschedule if client appears to be flagging, agitated or needing to come back at a different time; take any changes on yourself (I have a headache, can we stop now and reschedule); apologize [for delays, inconveniences or other things that may be upsetting the client] even if you didn't do anything wrong;

o Re other accommodations: be aware of sensory stimuli such as dim lighting; make sure reception is not too crowded and not too loud; be on the lookout for arrival of client so they are not kept waiting; prepare the client so they know what to expect at a hearing

- No understanding or skills
- Some understanding and skills
- Extensive understanding and skills
- Other (please comment)

18. Have you had training on accommodations for working effectively with persons with mental illness?

- No training
- Some training
- Extensive training
- Other (please comment)

19. How important do you believe training on accommodations for working effectively with persons with mental illness is for IIIB and other civil legal services attorneys?

- Not important
- Somewhat important
- Very important

- 20. How would you rate your knowledge of psychiatric advance directives and ability to draft them?
- O No knowledge or skills
- O Some knowledge and skills
- Extensive knowledge and skills
- Other (please comment)

21. Have you had training on psychiatric advance directives and drafting them for elders?

\frown	No	trai	ini	na
	140	ua		ng

- O Some training
- Extensive training
- Other (please comment)

22. How important do you believe training on psychiatric advance directives and drafting them for elders is?

- Not important
- O Somewhat important
- Very important

23. How would you rate your knowledge, awareness, and skills in dealing with <u>ethical issues</u> in working with older persons with mental illness? (For example, focus on the client's decisional capabilities or capacity despite their mental illness; be careful not to allow stereotypes associated with aging and/or mental illness to drive your decisions concerning legal representation; be familiar with your state's statutes/case law regarding different legal standards of capacity; be knowledgeable about a lawyer's obligations under rules of professional conduct.)

- No knowledge, awareness, or skills
- Some understanding and skills
- Extensive understanding and skills
- Other (please comment)

24. Have you had training on ethical issues in working effectively with persons with mental illness?

\cap	No	training

- Some training
- Extensive training
- Other (please comment)

25. How important do you believe training on ethical issues is for working effectively with persons with mental illness?

Not important

Somewhat important

Very important

26. How would you rate your knowledge and awareness of <u>other resources in the community</u> that could assist in representing older persons with mental illness?

- O No knowledge or awareness
- Some knowledge and awareness
- Extensive knowledge and awareness
- Other (please comment)

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27. If you checked "Some" or "Extensive" knowledge and awareness, please provide examples of what those community resources are.

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28. Please share any other experience and/or comments you may have about older persons with mental illness and representing them.

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THANK YOU FOR TAKING TIME TO TAKE OUR SURVEY!

Appendix 8: Responses to IIIB Survey Question 27

Survey on Preparedness of legal services providers to serve elderly persons with Mental Illness

Q27 If you checked "Some" or "Extensive" knowledge and awareness, please provide examples of what those community resources are.

Answered: 38 Skipped: 14

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#	RESPONSES	DATE
1	Pyramid Studios (adult day services for special needs); Lifelinks on the Court (adult day services for special needs) via Sunrise Community (Community Based Residential Services/Supported Employment/Supported Living/Day program-see Lifelinks); Eastside Psychiatric Hospital (inpatient mental health treatment/care/services/etc); Capital Regional Behavioral Hospital (inpatient mental health treatment/care/services/etc); Capital Regional Behavioral Hospital (inpatient mental health treatment/care/services/etc); TMH Behavioral Unit (inpatient mental health treatment/care/services/etc); Apalachee Center (outpatient mental health treatment/care/services/etc); Pace (mental health treatment/care/services); Florida Therapy Services (mental health grief/victim counseling services); Florida Therapy Services (mental health counseling services); The Alzhiemer's Project (respite care services/care giver support services/training and education to caregivers); Alzhiemer's Association (enhanced care and support and reduce risk for those affected); Ability First/Center for Independent Living (Community Based- support services/care (community based- support services/respite care services/respite care services/care); The Bond Community Center (Health care/tele- psychiatry/social services/transportation/pharmacy); Office of Public Guardian; The Refuge House (emergency and transitional housing/crisis counseling services/legal assistance/individual and group counseling); The Kearney Center (meal services/emergency temporary shelter/daytime services/medical assistance/connect to community resources/provide free bus transportation passes/social services cares assistance); etc.	6/8/2020 11:07 AM
2	APS, 60plus hotline, NCLER, Justice in Aging, Department of Aging	6/4/2020 2:29 PM
3	AAAs/ADRCs, NAMI, local psychologists and psychiatrists, Disability Rights Florida, community behavioral health	5/31/2020 8:13 PM
4	Homeless shelters and DV shelters; Ability first	5/31/2020 6:11 PM
5	In house webinars- NAMI traning	5/31/2020 3:41 PM
6	NJDMHAS, Bridgeway, Newbridge, Easter Seals, CMHCs, local hospitals, numerous social service agencies	5/29/2020 4:24 PM
7	Dept. of Elder Affairs and other state resources	5/29/2020 11:49 AM
8	Local mental health professionals. NAMI. Mental Health Association of Central Florida; Orlando Health. Department of Elder Affairs	5/29/2020 9:41 AM
9	Hospital social workers; local public and private mental health facilities; personal acquaintance with mental health professionals willing to do pro bono work; family members with post- graduate training in social work willing to consult on a pro bono basis.	5/27/2020 5:10 PM
10	VIA Link COA Resources Mental Health Association Resources	5/27/2020 3:54 PM
11	webinars and in person trainings	5/27/2020 8:34 AM
12	Office on Aging, Senior centers, DSS, Community Action Agencies	5/26/2020 6:57 PM
13	Dept of Aging and Disability Services, Dept of Social Services, the Arc, Belle Machre, Coordinating Center,	5/26/2020 6:47 PM
14	Mental Health counselors	5/26/2020 5:12 PM
15	I know about a few of the resources through our local homeless shelter, our hospitals/mental health facilities and additional resources within church groups.	5/26/2020 11:14 AM
16	Community Health Law Project Bar Association Section on Elder Rights NJ Mental Health Association Behavioral Resource Center - Inspira & Penn	5/26/2020 9:11 AM
17	Disability Law Center, NAMI,	5/22/2020 5:03 PM
18	Central Jersey Legal Services; Community Health Law Project; Jewish Family Services, Community Access Unlimited; Oaks Integrated Care; etc	5/22/2020 1:00 PM
19	Office of adult protective Services, Behavioral health services at University Hospital	5/22/2020 12:33 PM
20	local agencies that provide social worker assistance, rental assistance, hospitals which provide assistance for our clients and court resources.	5/21/2020 4:34 PM
21	Community Health Law Project, CBH Cares-Mental Health Center	5/21/2020 4:07 PM

22	NAMI, behavioral health advocates program, our state protection and advocacy org, CILs, staff at community mental health providers	5/21/2020 3:49 PM
23	Three Rivers; NCLER	5/21/2020 11:28 AM
24	Resources such as Legal Aid's Disability Integration Project and Georgia Advocacy Office which focus on these issues for clients.	5/21/2020 10:55 AM
25	Senior Center, Justice in Aging	5/20/2020 5:36 PM
26	Mental health service providers through local elderly affairs division.	5/20/2020 4:12 PM
27	United Way Riveredge Navicent Health Rescue Mission Daybreak Loaves and Fishes	5/20/2020 3:37 PM
28	providers of free/local cost mental health services; home health agencies; caregiver support resources; meal sites; guardianship program	5/20/2020 1:19 PM
29	did not check extensive knowledge of community resources	5/20/2020 1:04 PM
30	Local mental health facilities that work with people of all incomes and insurance statuses. Medication programs for people without insurance.	5/20/2020 12:55 PM
31	211 Appalachee Center Hotlines to call for help	5/20/2020 12:42 PM
32	NAMI, Family Connections, Happy Hour	5/20/2020 12:39 PM
33	Partnerships with mental health providers	5/20/2020 12:35 PM
34	New Horizons, The Bradley Center, The Family Center	5/20/2020 10:17 AM
35	Community mental health center Day center for persons with mental challenges Local AAA agency	5/20/2020 10:11 AM
36	Other non profit agencies and care providers.	5/20/2020 9:21 AM
37	Am aware of our primary mental health providers, memory disorder providers, elder services providers	5/20/2020 9:16 AM
38	Crisis Center	5/20/2020 9:01 AM

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Appendix 9: Responses to IIIB Survey Question 28

Survey on Preparedness of legal services providers to serve elderly persons with Mental Illness

Q28 Please share any other experience and/or comments you may have about older persons with mental illness and representing them.

Answered: 25 Skipped: 27

Survey on Preparedness of legal services providers to serve elderly persons with Mental Illness

#	RESPONSES	DATE
1	I have many family members (living and no longer living) who have mental illness (mentally ill, dementia, and alzhiemer's). I have learned a lot being around them and have also educated myself about their varying needs. I also have 1 adult child who is profoundly disabled (mentally ill) and I have a full guardianship over him. I have a younger son who has significant health needs (both mentally ill/health care related). I have had decades of training in the care of both of my children, which has significantly helped me with my employment and work with people who have mental illness. I have had years of education in college and decades of education by attending continuing education courses (through work and outside of work), and also through my work with these special people over the past several decades. They are very special people and have many obstacles to overcome on a daily basis. The more you educate yourself about their mental health needs, the more knowledge you will have to effectively communicate with them and further better assist them with their needs. If you are able to volunteer and/or help in their community (the more time you spend around them), can help you better understand some of their challenges and how they communicate and their range of understanding (now this varies per individual and their varying needs). They do not always communicate in the same way as others. It is good to remember that when working with them. It is helpful to really listen to them and be patient with them. Additionally it is helpful to be flexible in your approach in working with their varying needs.	6/8/2020 11:37 AM
2	Customer service rep in the past and currently a paralegal	6/1/2020 1:39 PM
3	Training is absolutely necessary to help remove the stigma of mental illness for legal aid attorneys. It is too easy to think that someone with a mental illness can't participate in their representation, yet the ethical bar for that is fairly low.	5/31/2020 8:16 PM
4	Can be a difficult and very time consuming process.	5/31/2020 3:42 PM
5	In housing, very easy for them to be taken advantage of and have civil rights violated. Actions associated or complications from mental illness can also jeopardize housing.	5/29/2020 9:42 AM
6	Over the past 36 years in this practice I have had numerous clients with various degrees of mental impairment. Sometimes these could be accommodated to accomplish the client's objectives, other times not. As a supervisor of other attorneys, having to work with them through their own conditions has helped me to understand the conditions better, how they affect people on a day-to-day basis, and how to work around those limitations.	5/27/2020 5:12 PM
7	Can be very frustrating—especially when baseless complaints get filed. I had one senior going through dimentia who filed the same complaint regarding the services I provided once a year for three straight years. I had to take the time to address each complaint. Takes patience.	5/26/2020 6:59 PM
8	I think the most important thing is to be patient and understanding.	5/26/2020 11:15 AM
9	We take our ethical obligations to all seniors very seriously. When we believe there are mental health issues we reach out to the office on Aging and other partners for assistance. The last thing we want to do is to creat any additional stress on our seniors	5/26/2020 9:13 AM
10	The importance of remaining calm and employing accommodations cannot be overemphasized.	5/22/2020 1:01 PM
11	As an advocate, I have been fighting to have the courts recognise that the process of aging is often one and quite universal of diminishing capacity. Hence the need for greater understanding and accomodation.	5/22/2020 12:39 PM
12	I think training is essential	5/21/2020 9:03 PM
13	It can be very challenging especially during the pandemic but the clients need us and it is well worth helping them.	5/21/2020 4:35 PM
14	I think more training is needed about older persons with mental illness and representing them. My prior experience as an attorney representing the disabled helped but more training would definitely be useful.	5/21/2020 4:10 PM
15	I think it's been particularly valuable to get training on distinguishing early signs of dementia from psychiatric conditions in our older clients. An attorney can be among the few people an older person confides in that can reveal both memory and confusion stuff as well as paranoia and delusions. We need to learn how to accommodate such issues in serving the client, but	5/21/2020 3:55 PM

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	also what resources are available and our ethical duties and limits regarding connecting with such resources.	
16	I once had a client that thought I was a federal agent and I was recording our conversation. He stated the television had been talking to him. I was able to properly and effectively reschedule the meeting. The client was not taking his medication.	5/20/2020 3:39 PM
17	Adequate healthcare coverage has become a major issue for our older persons.	5/20/2020 2:38 PM
18	I am not an Attorney and I do not represent clients with Mental illness.	5/20/2020 12:39 PM
19	need more training on capacity issues	5/20/2020 10:56 AM
20	I would welcome more extensive training on these issues, for myself and our other program attorneys.	5/20/2020 10:45 AM
21	I think that often times older folks with mental illness are confused with folks who suffer from dementia or alzheimers. We need to be more aware that seniors may have had mental illness issues their entire lives and that it is not a new condition associated with aging.	5/20/2020 10:19 AM
22	As a legal services attorney, I am trained to work with clients of any age who have mental challenges. I could use more training, but a lot of the training we get to serve our regular client base translates to this situation.	5/20/2020 10:13 AM
23	It can be very difficult especially when the client wants you to do something that you believe the client will regret and is not in the client's best interest.	5/20/2020 9:49 AM
24	I find it is imperative to be patient and remember that the professional staff hold the ability to direct the conversations and ultimately control how effective the relationship will be. Staying focused on facts and marrying what is available to help the individual is the moral responsibility in this type of relationship.	5/20/2020 9:24 AM
25	Very difficult to determine when a senior with mental disability can sufficiently form an attorney/client relationship.	5/20/2020 9:02 AM

also what resources are available and our ethical duties and limits regarding connecting with

Appendix 10: Laurie Hallmark's Training Video: Communicating with People with Serious Mental Illness

The training video on *Communicating with People with Serious Mental Illness* was an unexpected, but very important, part of our project. It was conducted for us by Laurie Hallmark, a legal services attorney for Texas RioGrande Legal Aid whose practice is focused on helping clients with mental illness. She was also one of our key informants and was extremely enthusiastic about our project from the moment she heard about it and wanted to help as much as possible. During our interviews with her, she referred to this training and graciously offered to conduct it for us, agreed to allow us to record it and to copy/disseminate it via USB drives. In total, we distributed 231 copies of the USB throughout the OAA legal services, aging and advocacy network.

For others who may be interested in viewing this training, it will be posted on The Center for Social Gerontology's website.