

**St. Vincent's House and
Galveston Island Community Research Advisory
Committee (GICRAC)**

**Community Bioethics Dialogue: Mental Health
and Seniors**

Final Report March 28, 2016

*A Partnership between St. Vincent's House and the Galveston Island
Community Research Advisory Committee (GICRAC), Galveston, and
the
Institute for the Medical Humanities, University of Texas Medical
Branch, Galveston*

This project was supported by grant number R24HS022134 from the Agency for Healthcare Research and Quality. The content is solely the responsibility of the authors and does not represent the official views of the Agency for Healthcare Research and Quality.

St. Vincent's House and Galveston Island Community Research Advisory

Committee (GICRAC)

Community Bioethics Dialogue: Mental Health and Seniors

Final Report, March 28, 2016

Introduction

To carry out the project, an Academic Support Team from University of Texas Medical Branch-Galveston (UTMB) formed a partnership with participants from St. Vincent's House (St. Vincent's) and the Galveston Island Community Research Advisory Committee (GICRAC). Most of the participants had previously participated in Community Bioethics Dialogues on Patient-Centered Outcomes Research (PCOR) and Comparative Effectiveness Research (CER). During this second round of dialogues, the participants elected to consider mental health, a topic considered to be of critical interest to the community, with the goal of learning more about various issues and the implications, as well as considering actions needed to address some of the problems. The ethical questions addressed by the group included the following:

- What are the critical issues in mental health for seniors?
- What is the role of health care system in supporting mental health for seniors?
- What is the role for various constituencies (patients, families, caregivers, and government) in managing mental health?

Our Process

The Academic Support Team met with representatives from St. Vincent's to plan the second round of dialogues. A number of topics were considered, but after extensive discussions, the topic of "Mental Health and Aging" was selected as being most important to participants due to its impact on the community. A number of us have faced issues with friends and family

experiencing mental health issues. In addition, we are concerned with various social issues such as the increase in mental health problems for those in jails and prisons. Once the main topic was selected, more discussions ensued to identify the details within mental health that we would consider. Following these discussions, we selected the following five areas as being the most interesting: general mental health and seniors; brain decline; caregiver issues; medications; and downstream issues (implications for the community).

St. Vincent's executive leadership oversaw the recruitment of participants from the organization and provided meeting facilities. When a number of participants from the first round in 2014 were unable to attend the sessions on mental health, participants from another community group whose first round was held in 2015, GICRAC, were invited to join. The combined group was divided equally from participants representing St. Vincent's and GICRAC, although some belonged to both. As awarded in the original Patient-Centered Outcomes Research (PCOR) grant, the project was overseen by the Sealy Center on Aging at UTMB and participants were 65 years of age or older. GICRAC's executive director was the facilitator for the combined group, and the Academic Support Team provided facilitator training.

Prior to the start of the dialogues, the Academic Support Team compiled a list of articles from medical journals and the lay press related to ethical issues in mental health and seniors (Appendix 1). The original round of dialogues covering PCOR and CER held in 2014 (St. Vincent's) and 2015 (GICRAC) occurred for two hours each week. In the planning sessions for the round on Mental Health and Seniors, participants asked if it would be possible to include guest speakers who were knowledgeable on the various topics, expressing the willingness to meet for an additional hour each week. Consequently, the dialogues occurred for three hours each week for five weeks during January and February 2016. Case studies formed the major basis for

discussion during each session (Appendix 2). We were also encouraged to do independent research and to discuss our deliberations with friends and family in between sessions. The Academic Support Team provided a recorder, and other members of the Academic Support Team attended and took notes during sessions.

Before the final dialogue session, the Academic Support Team compiled a list of ethical values taken from notes during Sessions 1-5. The list was provided to us prior to Session 6 and we were asked to agree or disagree with each ethical value statement, and if we agreed, to rank the statement as having high, medium, or low priority. We discussed the list extensively during Session 6, and the results formed the basis for the draft report, which was presented to us prior to the discussion on March 17, 2016, and any further disagreements resolved at that time. This final report is the result.

Major Ethical Conclusions

The statements in this section include ethical values for which we were nearly unanimous (at least 11 of 12 voting members) to include, and to which all or most of us assigned the highest priority.

System Considerations. Overall, we believe that mental health issues are just as important as physical health, and the absence of good mental health care is a critical issue in the community. When individuals suffer from poor mental health, the community is affected. As an example, we do not believe that jails should be used as a repository for those suffering with mental health issues. Other issues that should be addressed include the following:

- We believe that most people prefer to remain in their own homes as they age, and this should be a policy priority for programs that support those in this category. We learned of the existence of groups such as Libbie's Place, where seniors can go for

organized activities during the day, enabling them to remain in their own homes.

One of our members is already taking advantage of this resource for a family member, which is providing respite for caregivers.

- Information should be available to individuals and families regarding common aging issues, including the role that care facilities play when remaining at home is not an option. As an example, we believe that care facilities that do not meet regulatory requirements, and have experienced problems, should be reported in a manner that is accessible to all. In addition, the process for resolving complaints needs to be clear and accessible.
- When health care facilities are needed, it is typically a stressful time for the individual and/or their families. As a result, the rights and responsibilities for attending those facilities, including financial obligations for the individual's families, both now and in the future, needs to be communicated in a forthright and understandable manner. As an example, if a person is admitted to a care facility under Medicaid, their estate may be liable for payment, and the terms need to be made clear. Several of us have experienced issues after a family member's death, learning that assets are being attached to pay for care.
- Health care providers need to be trained, licensed (where appropriate), and paid fairly to serve the aging populace.

Role of Constituents. We believe that family members are responsible for caring for their loved ones, including making sure that mental health services are sought when needed. Families are responsible for looking after each other. However, the community, including the government, should provide the framework for making sure that needed services are available.

This can include, but is not limited to, providing incentives for establishing local senior centers. Finally, we believe that everyone should make plans for their own future. This includes involving family members and preparing plans in writing through advance directives so that the individual's wishes are upheld. In learning about this, several of us have made the effort to complete our own directives and are encouraging our friends and families to do the same. We are also advocating in our own communities – one participant is assistant manager in a seniors' complex, and got all of the residents to get families involved in their advance care planning as a direct result of these dialogues.

Other Issues. Cost issues are present in every sector of medicine, especially the availability of medications. We view the cost of medications as a critical issue that needs to be addressed to assure affordability. As an example, we believe that Medicare and Medicaid should issue bids for common medications in order to manage costs more effectively. In addition, we do not believe that individuals should be destitute in order to qualify for Medicaid care facilities. Some of us have experienced situations where care facilities were needed, but were not affordable, and asset/income thresholds were too high to qualify for Medicaid. This is not fair for working families.

Additional Ethical Issues

A number of other discussion topics did not reach consensus on their importance, but were still considered to be of sufficient significance to include in this report. These topics fell in the categories of availability of care within communities, access to training, issues within the political system, the role of news services, responsibilities for care facilities, and the role of government policies:

- Communities have a responsibility to protect the elderly and to remind everyone that

all of us are aging, and many will need some kind of supportive care. As recognition of this fact, many of us believe that high school students should have a class on the stages of life, and be encouraged to serve as volunteers in roles that acquaint them with older people. One of us remembers a “candy striper” program in hospitals, where young people served and had an opportunity to earn scholarships. This type of program should be encouraged so that all can be informed regarding issues associated with aging.

- All health care workers should receive specialized training in geriatrics and mental health. In particular, more physicians should be encouraged to train as geriatricians, with incentives provided to do so. In addition, most of us believe that those who do volunteer work in various outlets such as churches should have access to training in order to be able to identify those needing specialized mental health services.
- **Lobbyists for pharmaceutical and insurance companies have no place in health care, and should be disallowed.** In addition, campaign contributions should be limited for those who serve the public health sector.
- News agencies have an obligation to provide balanced information on mental health issues, especially among seniors.
- Care facilities should provide an easy forum for resolving care issues without having to resort to mediation or the courts. We believe that information should be provided to users on how to address the system, because most of us do not know what we need to know about services until after the knowledge is needed. In addition, the Federal government should provide incentives for the construction of more high quality care facilities in major areas in all states.

- Social Security and Medicare/Medicaid should be expanded to widen the safety net for mental health care. We believe that Texas legislators who chose to pass on the expansion of Medicaid made a big mistake, and should reverse their position. In addition, governmental agencies should work with private organizations to improve services to those with mental health issues.

Comments on the Community Bioethics Dialogues

These sessions provided a unique opportunity to learn more about mental health issues in our community and in broader society. Going forward, we would like to see more attention paid to the issue of mental health and aging, knowing that many of us may experience problems or will need to care for family members.

- This was my second one, and I enjoyed meeting new people. It was helpful to learn about mental illness. One family had dementia, and didn't know how to address it. If anything comes along, I am prepared. It has really been helpful.
- I have learned a lot. Even though I worked in the field, learning from the people who came to speak to us – being able to learn first-hand was very helpful. I enjoyed this session because it bore home to me.
- It has been very informative. Having gone through it gives me insight what I could have done if I knew about it. Now I have individuals with whom I can share where to go and some of the pitfalls. I am able to share some of the avenues.
- I'm always about the learning, and this is what it is all about. When we are able to break it down, there is a lot more stuff you need to know. I might not have paid attention to people before, but now I will. Learning about Libbie's Place and Alice was a big help – she had the connections to help my daughter's father. He is in there, and is liking it – it is

working for him. The same day she called me, she contacted the VA, and it was on, with benefits paid by the VA. He's not just around us – he is out and proud of his exercise. I appreciate it.

- I didn't know about Libbie's Place until Alice was here. I could have used it, but didn't know about it.
- I've been blessed again to be a participant in the program, and it has been an eye-opener. It has been informative, and given me enough to make decisions for myself, and I am able to share good, important information. Libbie's place is very good. Thanks for the invite.
- I have enjoyed the program very much, and it has helped me with understanding my mother-in-law's and my husband's medications. It has helped me when they change her medicines. I ask why the doctor wants to change the medicine if it is working.
- Even as the facilitator, the interaction is good, but for some of the things that we have discussed, being with my mother and aunt, talking about things pushed me to work with my mother about powers of attorney. I hadn't thought about that – we just had not had the conversation, so we put that paperwork into place. It allowed me to look at the situation because we do not know what is going to happen down the road. As facilitator, I didn't think I would walk out with a piece that would help me. I will bring it up with the GICRAC Board to provide some additional information to the community. It can happen. We just need to pack the place and get the folk. I am all about getting it out there for people to use.
- The power of attorney – don't know about it unless someone talks to you. When I retired, my financial adviser pushed me to do that. When you get the information, you

share it with people. All of this is real valuable. I hope we can do something with the videos. Need to have an open forum – public forum to discuss issues.

- As Assistant Manager for a senior complex, I called a meeting of all the tenants and family members and had paperwork for everyone to fill out to make sure they had a will and power of attorney (medical and financial), and put it in their files. Everybody was so surprised and interested in what they needed to do. It turned out very well. I have used these meetings to be successful for my work.
- I have informed my children that they need to know about the need for filling out the paperwork. I got all of them cleared and everyone agreed. If anything happens to me, I don't want anyone to cry. I also got a couple of my friends to do that.
- Since coming here, I have taken the step to plan the way I wanted to go – it's all down on paper and all set. This is from listening to what everyone has said.
- I went to a revival, and the preacher put everything from mental health in the Scripture, and was preaching about it. We are on the right page in here, and that confirms it for me.
- We are breaking the cycle, because the things that we are talking about in here haven't been talked about. The things that have been taboo for us, going forward, is coming down. This is why it has been so important. Talk about death. Talk about mental health. We sit down and have a conversation that is very important.
- The knowledge can be shared exponentially – we have to think about that and keep it going forward.
- We want to have sustainability, so that when the grant goes away, we can keep it going, and this has staying power.
- This opened up some other stuff – I have been seeing more articles in the newspaper,

such as the information on the special mental health courts. I don't know if it's just me paying more attention. It has opened up my eyes that there is a lot of information.

- One of my many things that peaked my interest is how intelligent we are in discussing these issues. It is a blessing to know that we have all this knowledge. There are so many benefits that we have received – it has been a great experience and very educational.

Participants:

Laurence Franklin

Irma Moore

Mozellar Petteway

Winnie Simpson

Mary Alexander

Pauline Williams

Carol Ann Guidry

Pam Jackson

Jann Compton

Jama J. Shabazz

Mary J. McGaskey

Sandra Tousant

Facilitator:

John Cooks

Academic Support Team:

Jerome Crowder

Peggy Determeyer

Participant signatures:

Laurence Franklin

Irma Moore

Mozellar Petteway

Winnie Simpson

Mary Alexander

Pauline Williams

Carol Ann Guidry

Pam Jackson

Jann Compton

Jama J. Shabazz

Mary J. McGaskey

Sandra Tousant

John Cooks

Appendix 1.

List of Background Readings and Session Topics

Community Bioethics Dialogues Mental Health Issues – Topic List and Readings

Week 1 Overview of Mental Health Issues

Guest Speaker: Dr. Mukaila Raji, Professor & Director, Division of Geriatric Medicine, UTMB

Readings

Mental Health Myths and Facts, <http://www.mentalhealth.gov/basics/myths-facts/>

Reynolds, Kristin, Robert H. Pietrzak, Renee El-Gabalawy, Corey S. Mackenzie, and Jitender Sareen. "Prevalence of Psychiatric Disorders in U.S. Older Adults: Findings from a Nationally Representative Survey." *World Psychiatry* 14, no. 1 (2015): 74-81.

Robinson, Karen M. "Policy Issues in Mental Health among the Elderly." *Nursing Clinics of North America* 45, no. 4 (2010): 627-34, vii.

Directors, Centers for Disease Control and Prevention and National Association of Chronic Disease. *The State of Mental Health and Aging in America, Issue Brief 1: What Do the Data Tell Us?* Atlanta, GA: National Association of Chronic Disease Directors, 2008.

Week 2 Brain Decline

Guest Speaker: Dr. Oma Morey, Sr. Medical Educator – Educational Development, Internal Medicine

Case Study

The research-based reader's theater, *The Long Journey Home: Caring for a Loved One with Dementia*, is based on the 2-Act play of the same name, both written by Dr. Oma Morey. The play depicts true stories of 10 caregivers in the Houston/Galveston area who have taken care of parents, children, and spouses with dementia/Alzheimer's, and who participated in a qualitative study conducted by Dr. Morey. The dialogue comes directly from comments made in the interviews in order to keep true to the stories. The reader's theater was developed by excerpting eight scenes from the original play. A narrator was added to explain what was happening in the scenes so the listener can follow the movement that was performed in the stage production. Members of the University of Texas Medical Branch and the local acting community read the eight roles in the reader's theater, expressing both the words and emotions portrayed in the play. The play is currently performed for incoming medical students and has been part of a course for the past 6 years.

Readings

Causes of Brain Decline, matrix developed by Peggy Determeyer, PhD Candidate at the Institute for the Medical Humanities

Mayor, Susan. "Brain Training, Exercise, and Healthy Eating Slow Cognitive Decline in Elderly People at Risk, Study Finds." *BMJ* 350 (2015): h1386.

Week 3 Caregiver Issues

Guest Speaker: Alice Williams, MS, LBSW, Executive Director, Libbie's Place Senior Day Program

Readings

Lin, Mei-Chen, and Howard Giles. "The Dark Side of Family Communication: A Communication Model of Elder Abuse and Neglect." *International Psychogeriatrics* 25, no. 8 (2013): 1275-90.

National Association for Caregiving, in Association with AARP. *Caregiving in the Us: Executive Summary*. MetLife Foundation, 2009.

Neal, Margaret B. and Donna L. Wagner. *Working Caregivers: Issues, Challenges, and Opportunities for the Aging Network*. National Family Caregiver Support Program 2000.

Week 4 Medication Issues

Guest Speaker: Andrea Wirt, Nurse Practitioner, UTMB

Readings

Culberson, John W., and Martin Ziska. "Prescription Drug Misuse/Abuse in the Elderly." *Geriatrics* 63, no. 9 (2008): 22-31.

Lynch, Tom. "Medication Costs as a Primary Cause of Nonadherence in the Elderly." *Consultant Pharmacist* 21, no. 2 (2006): 143-6.

Naci, Huseyin, Stephen B. Soumerai, Dennis Ross-Degnan, Fang Zhang, Becky A. Briesacher, Jerry H. Gurwitz, and Jeanne M. Madden. "Medication Affordability Gains Following Medicare Part D Are Eroding among Elderly with Multiple Chronic Conditions." *Health Affairs* 33, no. 8 (2014): 1435-43.

Pfizer, Inc. *Medication Safety for the Elderly: A Guide for Patients and Caregivers*. 2011. [www.pfizer.com/files/...safety/4-6 Med Safety for Elderly.pdf](http://www.pfizer.com/files/...safety/4-6_Med_Safety_for_Elderly.pdf)

Week 5 Downstream Issues

Guest Speaker: Dr. Jason Glenn and Captain Byron Frankland

Readings

Byron, Robert. "Criminals Need Mental Health Care." *Scientific American* 25, no. 2

(March 1, 2014).

National Alliance on Mental Illness. *A Guide to Mental Illness and the Criminal Justice System: A Systems Guide for Families and Consumers*. NAMI Office of Legal Affairs.

Parker, Lisa S., and Valerie B. Satkoske. "Ethical Dimensions of Disparities in Depression Research and Treatment in the Pharmacogenomic Era." *Journal of Law, Medicine & Ethics* 40, no. 4 (2012): 886-903.

James, Doris J. and Lauren E. Glaze. *Mental Health Problems of Prison and Jail Inmates*. Washington DC: US Department of Justice, 2006.

Week 6 Discussion of Values

Appendix 2.

Case Studies

Week 1 Case Study – Mental Health Decline

Your best friend comes to you with a problem. Her 83-year-old mother has been living alone and doing well. Recently, your friend was reviewing her mother's accounts and noticed that there were several bills that had been paid in duplicate, and a few checks were written to organizations that your friend did not recognize. When she questioned her mom, your friend did not hear satisfactory answers, especially for the checks written to organizations, saying that she has been watching "those nice people" on television, and they were asking for money to help children on the other side of the globe. Her mom did not remember paying the bills in duplicate at all, and does not remember seeing a positive balance on some bills. In addition, your friend has learned that her mom has stopped going to her friends' weekly canasta game, and knows that this is unusual since this has brought her a lot of pleasure. Finally, your friend notices that her mom's house is not as neat as it used to be. Your friend works full time and is not able to follow her mom every day, and asks for your advice.

- What are the priorities for your friend to consider? Why?
- How would you help her to identify solutions?
- What are the values to be considered in your friend's predicament?
- What are the policy issues, if any?

Week 2 Case Study: Reader's Theater, Dr. Oma Morey, UTMB

Week 3 Case Study – Caregiver Issues

Sam has been taking care of his wife ever since she was diagnosed with Alzheimer's two years ago. Until now, he has been coping with the day-to-day issues, although his four children are concerned that he is not taking care of himself. This is evidenced when Sam develops a heart condition and is hospitalized for several days. Upon returning home, his children insist that he arrange for help around his house, but Sam is concerned about finances, and does not take their advice. Three of the four children live in other cities. Sam has been your friend for several years, and one day at lunch, he unloads on you about his situation, not knowing what to do

- What are the priorities for your friend to consider? Why?
- How would you help him to identify solutions?
- What are the values to be considered in your friend's predicament?
- What are the policy issues, if any?

Week 4 Case Study – Medication Issues

You and Mary Ellen have been friends for over 20 years. One day at lunch, you notice that she is not as alert as usual. You ask how she has been doing, and Mary Ellen confides that she has been having some health issues and seeing several doctors, one of which has prescribed blood pressure medicine. Recently you read an article noting that seniors are at risk for having medicines over-prescribed to them by doctors. You ask Mary Ellen about the other medications she is taking, and learn that there are several that are listed in the article that may cause problems when taken at the same time. Mary Ellen becomes defensive, and says that she trusts her physicians.

- What are the priorities for your friend to consider? Why?
- How would you help him to identify solutions?
- What are the values to be considered in your friend's predicament?
- What are the policy issues, if any?

Week 5 Case Study – Downstream Issues

Your church has recently established a ministry to homeless people. One of the services is providing a warm lunch for them on three days out of the week. You begin volunteering, and when you are serving food one day, you notice that several of the clients are acting out by shouting at the wall and not responding well to questions. Your church has not prepared well enough to address people with such problems – you thought you were just doing a good deed by providing meals, and instead you find your church committed to much more than that.

- What are the priorities for your congregation to consider? Why?
- How would you help them to identify solutions?
- What are the values to be considered in providing services to the homeless?
- What are the policy issues, if any?

Participant signatures:

Laurence Franklin *Laurence Franklin*
Irma Moore *Irma Moore*
Mozellar Petteway *Mozellar Petteway*
Winnie Simpson *Winnie Simpson*
Mary Alexander *Mary Alexander*
Pauline Williams *Pauline Williams*
Carol Ann Guidry *Carol Ann Guidry*
Pam Jackson *Pam Jackson*
Jann Compton *Jann Compton* *Jann Compton 23 @ Comcast.
Com*
Jama J. Shabazz *Jama J. Shabazz*
Mary J. McGaskey *Mary J. McGaskey*
Sandra Tousant *Sandra Tousant*
John Cooks *John Cooks*