

## Spring 2013

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**FOCUS Editor: Amy Haddad, PhD; Associate Editor: Kate Tworek, BA**

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**Director's Report - Maintaining Quality While Planning for the Future**  
**by Amy Haddad, PhD**

For the past four years, the Center has focused considerable energy, resources, and attention on the development and launching of two fully online graduate programs, the Master of Science in Health Care Ethics in 2009 and the Master of Public Health in January of 2013. At the same time, Center faculty continued to teach in the various health sciences programs at Creighton, presented papers and delivered keynote addresses at national conferences, served as consultants to hospitals and health care systems locally and nationally, contributed to scholarly work in ethics, policy and public health, and maintained an active role in service to the wider Creighton family and community. Throughout all of this, there was little time for planning beyond what needed to be done in the immediate future, e.g., proposals for programs needed to be developed, faculty hired, students recruited, and courses developed from the ground up. Center faculty and staff relied on the three guiding principles that were developed on the occasion of the 20th anniversary of the Center in 1995. As you can imagine with a team of highly educated and often passionate faculty and staff members, there was considerable debate about every word in the following principles:



**Amy M. Haddad, PhD, Director of the Center for Health Policy & Ethics**

- Advancing an ethic of service, justice and compassion for others.
- Contributing to the formation of ethically committed health professionals.
- Fostering intellectual exchange in solidarity with the human community.

These guiding principles have been the basis for some updates to a general strategic plan for the Center in the intervening years, but now, as with the change of seasons or the arrival of the seven-year locusts, it is time to plan in earnest. There are several reasons for focusing on strategic planning at this juncture. Although staff and faculty have a basic shared understanding of and commitment to the mission of the Center which is grounded in social justice, the introduction of a new program in a related but clearly different discipline, public health, has cast a different light on the identity of the Center. Therefore, this is an appropriate time to confirm or revise the mission statement and other public expressions of the Center's mission. Furthermore, the current pattern of the diversity of activities of the Center faculty, individually and collectively, as well as the staff who coordinate many of the community activities of the Center such as the roundtable discussions, visiting scholar lectures, and the Women and Health Lecture in the fall, may, over time, dilute efforts to focus on the core mission of the Center. In other words, with finite resources, decisions need to be made on priorities that will best meet the Center's and University's goals.

The first strategic planning session was held in August 2012. The August planning retreat began with a review of the history of the Center then moved on to exercises that encouraged examination of the best of the past and present in four areas: strengths, opportunities, aspirations and results. Several concrete action steps resulted from the August meeting including the development of a new graduate Certificate in Health Care Ethics that was inaugurated in April of 2013. The August planning retreat set the stage for the second phase of the planning process which is to revisit the mission, vision and guiding principles of the Center in order to establish priorities for what we need to invest as far as time, partners, resources, what we are going to do, who we intend to reach, and what outcomes we anticipate. A second day-long planning retreat was held in April at which time all members of the Center were given the opportunity to critically appraise the present and future as they are represented in the mission, vision and guiding principles of the Center. The underlying driving force throughout all of the planning is to respect what the Center has accomplished in the past, maintain the quality of the programs and activities we currently provide, and secure a strong foundation for the future.

## ***Experiencing Joy in Northeast India***

**by Beth Furlong, PhD and Dee Sledge, MA**

*I slept and dreamt that life was joy. I awoke and saw that life was service. I acted and behold, service was joy.* These are the words of Nobel Prize winner, Rabindranath Tagore of Calcutta, India. The invitation to service came from Anand Pereria, SJ, a graduate of Creighton University's EdD program and a member of the Jesuit community from the Kohima Region of Northeast India. Service did indeed turn to joy for Beth Furlong and Dee Sledge from CHPE, along with members of St. John's Parish, the Werner Institute at Creighton, Creighton School of Medicine, and University of Nebraska Medical Center. On December 26, 2012 the eight-person group embarked on a 36-hour journey to Guwahati, Assam, India, one of Seven Sister States of Northeast India. Northeast India is comprised of indigenous communities who are multi-cultural, multi-linguistic, and multi-religious. We witnessed the Jesuits' missionary passion in their partnership ministries with the poor and marginalized. We observed the joy of the tribal people in welcoming us with song and laughter; the joy of the children while they listened attentively to our stories about our parishes; the joy of Church elders as we shared our faith; and the joy of the nurses as they tirelessly ministered to the sick and infirm. Our guide was Melvil Pereria, SJ, a CHPE Contributed Services Faculty member and a former CHPE Senior Visiting Fellow. The group visited schools, parishes, an orphanage, medical clinics, a legal clinic, and the North Eastern Social Research Center (NESRC) where Fr. Melvil is the director.



**Travel Group with some of the Kohima Jesuits in Guwahati, Assam, India**

Against a backdrop of the lower Himalayan Mountains and singular geographic beauty, we focused our attention on learning and reflecting on how best to strengthen and maximize the partnership activities between the Kohima Province of Northeast India and the Midwest states' Wisconsin Province. For 2013, our 'early January' travel group would be the first of five Nebraskan groups to travel there and assess how we can all strengthen the partnership.

While we plan the future, these are some outcomes the authors have realized: 1) an information video constructed by Dee which has now been viewed 150 times, 2) facilitation of a master's student in the CHPE's Master's in Health Care Ethics program to implement her Practicum course, 3) nomination of one of the Jesuit ministries, the NESRC for the 2013 Rockefeller Foundation Global Innovation Fund award, 4) sharing of information with a variety of groups, i.e., a presentation as part of the Office of Multi-Cultural Affairs Solidarity Series, etc., 5) "hands on" assistance with others seeking the necessary India visa, 6) sharing between two travel groups, 7) editing of manuscripts among faculty colleagues, and 8) a planned retreat for all the Nebraskan participants with a goal of sustained energy, collaboration, and future sustainable partnership activities.

In summary, we experienced what Teilhard de Chardin, SJ, wrote—"Joy is the most infallible sign of the presence of God."

## ***American Indian Talking Circles and Diabetes Self-Management*** ***by Marlene K. Wilken, RN, MN, PhD***

Historical changes to the Omaha Tribe were devastating to their social, economic and spiritual wellbeing not to mention the sacred relationship to the land base, which was ever dwindling. These historical changes over the last 60 years have contributed to the Omaha Tribe facing one of the biggest challenges today, diabetes. Talking Circles (TCs) have been around for centuries and are still practiced today by the Omaha Tribe. The TC is a Native American approach to experiential learning through the coming together of people for a specific purpose in a respectful and cohesive format. The TC participants sit in a circle, bring their problems or issues and then counsel and talk with one another until things are resolved. TCs are a culturally appropriate strategy to address diabetes self-management which requires a focus on changing individuals' attitudes, skills, and behavior. In addition, the TC helps to reinforce individuals' strengths and personal goals to ensure their continued ability to participate and contribute in activities that are meaningful to them and to improve their quality of life. This study used the TC as one intervention to improve diabetes self-management behaviors for American Indian study participants whose HbA1c's were higher than 7% as the goal for people with diabetes is a hemoglobin A1c less than 7. Each of the two groups of study participants met once a week for 12 weeks. The TC was facilitated by a tribal elder with well-controlled DM2 and experience as a TC leader. Permission to audio-tape the Talking Circles was given by the study participants when they were recruited for the study. The content of each of the 24 Talking Circle meetings was analyzed qualitatively by the PI and Co-I and an external audit was provided by an Omaha Tribe member who had extensive knowledge of and experiences with Talking Circles. This consultant reviewed each coded transcript for accuracy of the coded interpretations. Cultural themes significant to the TC participants were spirituality which included prayers, relationship to God (Wakonda) and blessings for those who were objects of the prayers. Additional themes or characteristics of the culture that were evident throughout the TC sessions were gratitude, sharing, and humor. The major topics of the discussions were the experiences of living with DM2. The subcategories of themes expressed included the challenges of having DM2. These challenges were: fatalism, denial, difficulties related to medication adherence and regimen compliance, achieving acceptance and the effects of DM2 on families. Another category was coping with DM2. Coping included reasons for participating in the TC, motivators for adherence to medication and dietary regimens, specific behaviors that promoted adherence, and the effects of adherence. Study participants consistently identified that what they liked best about the TC was the sharing, hearing others' stories, and knowing they were not alone.

Attendees at the CHPE Roundtable in November 2012 participated in a Talking Circle, led by Tribal Elder Rudi Mitchell. Dressed in Omaha Tribal attire, with all participants sitting in a circle, Dr. Mitchell explained the purpose and procedure for the TC. After the cedar ceremony and prayer, the sacred Eagle feather was passed to the first person on the left of Tribal Elder Mitchell. That individual read aloud a typed response given to them before the TC started. This response was taken from the TC transcripts of study participants and the collection of responses were representative of the themes identified by study participants. Once the person had read the response the eagle feather was passed to the next person until all participants in the circle had shared their response.



**Dr. Mitchell and Dr. Wilken**  
**This study funded by NIDDK grant**  
**IR34DK089473**

## Personnel News

by *Marybeth Goddard, MOL, BSBA*

### New MPH Faculty Member

CHPE is pleased to announce the addition of **Wei Vivian Zhuang**, PhD, as an Assistant Professor, in its Master of Public Health (MPH) program. Dr. Zhuang will design and teach courses in the MPH curriculum in the areas of epidemiology, biostatistics, and environmental health to motivate students' development of global perspectives about population and public health. Dr. Zhuang comes to CHPE from Boston University where she taught in the School of Public Health.



**Vivian Zhuang**

### Kudos! Several CHPE Faculty and Staff have recently been recognized by their peers:

**Dr. Jos Welie** is the 2011-2012 recipient of the Creighton University School of Medicine Exceptional Educator Award, October 26, 2012.



**Jos Welie**

**Dee Sledge**, MS, received on April 28, 2013, from Creighton University's Center for Student Integrity, the Blessed Peter Faber Integrity Award. Dee's nomination emphasized the ways in which she serves her community, distills common or right values from new relationships and life experiences, and displays leadership to help groups and individuals move towards something greater.



**Dee Sledge**

**Dr. Beth Furlong** received the Distinguished Service Award from the Nebraska Nurses Association, District II Chapter, November 12, 2012.



**Beth Furlong**

**Dr. Helen Chapple** was honored with the 2013 Association for Death Education and Counseling (ADEC) Service Award, April 26, 2013. The ADEC Service Award recognizes excellence in service to ADEC and contributions to the activities of the Association demonstrated by innovating association programs, conducting workshops, assisting with conferences, and serving the Association.



**Helen Chapple**

## ***Policy Testimony at Douglas County Board of Commissioners' Meetings***

***by Beth Furlong, PhD, JD, RN***

In August 2011 the Douglas County Board of Commissioners established a Blue Ribbon Committee to seek input, analysis, and recommendations regarding concerns as a part of its strategic planning process and for the Committee to review the operations of the Douglas County Health Center (Long term Care, Assisted Living and Support Services), and the Community Mental Health Center and General Assistance which includes the Primary Health Care Clinic (County Resolution No. 509, adopted August 2, 2011). Each of the seven Commissioners appointed two community members; Dr. Beth Furlong was appointed by Commissioner Pam Tusa. The Committee was directed to meet twice monthly in open meetings. In January 2012 the 14 Committee members gave three separate reports to the Commissioners as consensus had not been reached on all recommendations. During this six month period of public meetings, Dr. Furlong contributed in a variety of ways, i.e., verbally at all meetings, conducting a literature search on Evidence-Based Practice and research studies about care of the particular vulnerable populations involved, determining Best Practices, etc. (<http://www.douglascountyclerk.org/county-board-records/blue-ribbon-committee>; see January 18, 2012; Retrieved May 9, 2013).

The population of marginalized nursing home residents and patients at the above four health centers include some of the most vulnerable individuals in the Omaha area. They are poor, often without health insurance, employment, education, nor support systems. Further, for the residents of the Long term care center, these are residents who frequently have complex behavioral illness needs. The data noted by the Blue Ribbon Committee (as well as a later 2012 contracted external vendor for assessment, i.e., Health Management Associates (HMA)) was that there, literally, was no other placement facility in the greater Omaha area who would accept the residents being cared for in this Long term care center. In January 2012 Dr. Furlong and Committee colleague Patricia Zieg, attorney, summarized a 10-point recommendation list in their report which began with the ethical precept of 'not abandoning a vulnerable population' by recommending options that would avoid abandonment.

During Spring 2013 Dr. Furlong had 'public voice' again when she testified at two public meetings—1) the Special Public Hearing of the County Commissioners when they received the recommendations of the above external assessment vendor, HMA, and 2) a weekly County Commissioners' meeting when decision making was occurring about the future of the four health centers. Her voice, in all meetings, has been one of policy advocacy for the respective four vulnerable populations. Her participation, contributions, and public voice reflect her commitment to policy advocacy based on social justice and other ethical theories.

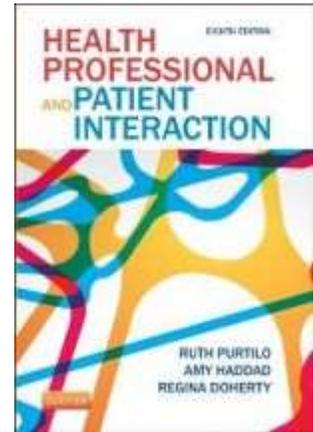
Sections introduce the patient's point of view, encourage critical thinking and promote the use of personal experience. Reflection topics encourage and challenge students to apply content to their own clinical experiences. In this new edition, health care terminology has been updated, and Doherty, a new author for this edition, has added an occupational theory perspective.

***New and Revised Edition of Health Professional and Patient Interaction***  
**by Amy Haddad, PhD**

The Center is pleased to announce the publication of the eighth edition of *Health Professional and Patient Interaction* by Elsevier Publishers. The book is co-authored by [Amy Haddad](#), Ph.D., the Director of the Center for Health Policy and Ethics; [Ruth Purtilo](#), Ph.D., a CHPE contributed-service faculty member and former CHPE Director; and Regina Doherty, Ph.D., Associate Professor at the MGH Institute of Health Professions. The book addresses a wide range of strategies for healthy and productive relationships between health professionals and patients.

The focus of the book has always been on the development of the student in a variety of health care professions. The first edition of *Health Professional and Patient Interaction* was published by Ruth Purtilo as the sole author in 1973. Dr. Haddad joined Dr. Purtilo as co-author of the fifth edition of the book in 1996. In the current edition, the authors use practical examples and scenarios to illustrate respectful, ethical and professional interactions with patients of different ages, cultures and levels of impairment, as well as in the context of various practice settings. The new edition points users to a companion website that features educator resources such as slide presentations and test questions. Additionally, there is expanded content on diversity that reflects the diverse patient populations served.

Sections introduce the patient's point of view, encourage critical thinking and promote the use of personal experience. Reflection topics encourage and challenge students to apply content to their own clinical experiences. In this new edition, health care terminology has been updated, and Doherty, a new author for this edition, has added an occupational theory perspective.



**Center for Health Policy and Ethics Collaborates with Alegant Creighton Health Ethics Center  
by Helen Shew, MBA, MS**

Alegant Creighton's Interdisciplinary Bioethics Education Committee (IBEC) hosted their annual conference for health care professionals on Friday, March 1, 2013 at Omaha's Scott Conference Center. The theme of this year's conference was "Providing Patient and Family-Centered Care at the End of Life", featuring keynote speaker Dr. Ira Byock. Dr. Byock is the director of Palliative Medicine at Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire and a Professor at the Geisel School of Medicine at Dartmouth. He is widely recognized as a national leader in the practice of medicine at the end of life. From 1996 through 2006, he served as Director for Promoting Excellence in End-of-Life Care, a national grant program of the Robert Wood Johnson Foundation. Dr. Byock has authored numerous articles on the ethics and practice of hospice, palliative and end-of-life care. His lecture the day of the conference was entitled "The Ethics and Practice of Loving Care".

Dr. Byock discussed precedents for loving care that already exist in pediatric and hospice care and how these might be incorporated more fully into end-of-life care. The goal being that as a community of health care providers, we view end-of-life care as a gift and an offering of the best we have in our minds and hearts. In addition to CHPE faculty and staff members serving on IBEC and assisting with conference planning, CHPE faculty member, [Helen Stanton Chapple](#), also presented at the conference. Dr. Chapple's engaging session, "End of Life Care Trends," highlighted her ongoing research into knowledge, attitudes and perceptions about end-of-life care in Nebraska. A panel session focused on practices and beliefs in regard to end-of-life care for various faith groups capped off the afternoon and generated much audience discussion.

The primary conference organizer was Leslie Kuhnel, Alegant Creighton's Ethics Center Director and Ethics Officer, who also chairs the Interdisciplinary Bioethics Education Committee. Ms. Kuhnel is a spring 2013 graduate of CHPE's [Master of Science in Health Care Ethics \(MSHCE\) program](#).

**While in Omaha, Dr Byock also presented a community lecture at Countryside Community Church's Center for Faith Studies. His lecture "Dying Well: Getting 'The Best Care Possible' Through the End of Life" took place on February 28, 2013 and can be heard here.**

**<http://kios.org/post/center-faith-studies-lecture-41513>**

**Dr. Byock's articles, opinion pieces and interviews along with other materials are available at this site:**

**<http://www.dyingwell.org/>**

***Roundtable on the Affordable Care Act & Mental Health Care***

Dr. Christy Rentmeester was invited to be one of the academicians in attendance at the 2013 Scattergood Behavioral Health Policy Roundtable on 25 April 2013 at the WHYY Media Commons in Philadelphia, Pennsylvania. Other participants were executive leaders in regional and national healthcare and insurance organizations, city and state government officials from New York and Pennsylvania, and members of Ivy League Behavioral Health consortium institutions. Attendees convened to illuminate key features of recent healthcare reform legislation that offers opportunities for improving mental health integration and outcomes. Next steps are to continue collaborating to develop strategies for stakeholders to respond to these opportunities and to generate and publicize web-based and press resources.

## Collaborations in Germany

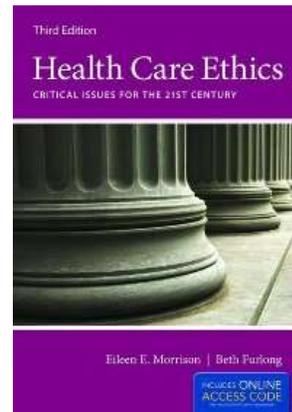
Dr. Christy Rentmeester joined an international collective of scholars and teachers to consider ethics and mental health in Germany in December 2012. Hosted by the Philosophisch-Theologische Hochschule (PTH) in the city of Vallendar in the Rhine Valley, the Mental Health Care and Ethics Working Conference convened the first of what will be established as a biennial meeting in Europe. Dr. Rentmeester's session emphasized interactions among healthcare professionals' attitudes, demeanors, and habits of perception on the quality of care of people with mental illnesses. While in Germany, Dr. Rentmeester also gave a lecture to graduate level nurses studying nursing pedagogy at PTH and spoke with clinical ethics committee members of Klinikum Region Hannover. The Mental Health Care and Ethics Working Conference was organized by former CHPE Visiting Scholars Lutz Schuetze and Jr. Prof. Dr. Helen Kohlen. Proceedings of the conference will appear in a forthcoming issue of the German bioethics journal *Ethik der Medizin*.



**Lutz Schuetze (Faculty, University of Applied Sciences and Arts, Hannover), Dr. Christy Rentmeester, and Dr. Carsten Dette (psychiatrist, Klinikum Region Hannover)**

## Health Care Ethics Book Updated by CHPE Faculty by Beth Furlong, PhD, JD, RN

In February 2013 the third edition of the book, *Health Care Ethics: Critical Issues for the 21st Century* was published. Dr. Eileen Morrison, Adjunct Faculty of CHPE, had been the editor of the first two editions. Dr. Beth Furlong, faculty member of CHPE, served as co-editor for this third edition. Included in the 21 contributing authors were the co-editors and a third faculty member connected to CHPE, Dr. Richard O'Brien, Professor Emeritus.



The book, aimed at graduate health science students, continued its organizational structure of 1) a section on the foundation of ethical theories and principles, 2) three sections on ethical issues at these different levels in cultures, i.e., individuals, organizations, and society, 3) ethical quandaries across the lifespan, 4) inclusion of issues raised by current national and state health care reform policies, and, 4) discussion of other emerging issues. The variety of authors with their diverse expert educational backgrounds and work experiences, some as clinical health providers, adds to the richness of the chapters. For both the students and the faculty members using the book as a course textbook, the discussion questions at the end of each chapter could facilitate enhanced understanding and reflections.

Implementation of the national Patient Protection and Affordable Care Act (PPACA) is in the national, state, and local news daily as state legislatures make decisions on Medicaid Expansion and Health Exchanges, Congressional representatives attempt repeal of the Act, etc. Because of this major emerging policy reform which affects millions of people, businesses, et al. in this country, there are two new chapters in this edition of the book on this topic. Dr. O'Brien contributed a chapter, "A New Era of Health: The Ethics of Healthcare Reform." Dr. Furlong furthered the concerns by contributing the chapter, "Healthcare Reform: What About Those Left Behind?"

In addition to being an editor for the first two editions and co-editor of this edition, Dr. Morrison contributed as co-author to four chapters on topics of ethics committees, spirituality and health care organizations, ethics of disaster planning, and emerging ethical issues. Besides being teaching colleagues at CHPE in the MSHCE program, Drs. Furlong and Morrison valued working collaboratively on this ethics book.

## **Alumni News**

We asked graduates of our MSHCE program to keep us posted on their new ventures. Here's what we've heard . . .

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### **From Jan Schnack:**

Jan Schnack, MSHCE'12, recently embarked on a new educational journey at Creighton University, pursuing a master's in theology. CHPE faculty member, Dr. Helen Chapple also invited Jan to join the steering committee for [It's All About the Conversation](#). "It is a state-wide coalition interested in removing obstacles to excellent care for dying patients," said Dr. Chapple. "Jan is helping us with planning for our booth at the State Fair."

### **From Adina DeWitt:**

Adina DeWitt, MSHCE'12, was part of the creation of and now chairs an ethics committee at Estes Park Medical Center. The committee's goal this year is to increase awareness among the medical center staff about the role of the committee and to review various hospital policies. Chairing the ethics committee is in addition to her long-held position as Lab Director. [Estes Park Medical Center](#)

**Graduates in Class of 2013**  
**by Sarah Lux, MS**

The Center for Health Policy & Ethics is proud to announce its Spring 2013 and Summer 2013 candidates for the Master of Science in Health Care Ethics degree:

**Spring 2013**

- Joseph Chebuhar\*
- Jeri Conboy
- Timothy Cotita\*
- Hannah Davis
- Leslie Kuhnel\*
- Ruth “Annie” MacLean
- Brandy Olson\*
- Llewellyn Powell\*
- Annie Walker\*
- Thomas Whetstone

**Summer 2013 (anticipated)**

- Marguerite “Peggy” Augustine
- Paul Babcock
- Lisa Burroughs
- Marisa Bustillo\*
- Regine Calvar\*
- Kristie Denne\*
- Alan Heimer\*
- Mary Homan\*
- Lynnette Johnson
- Mary Jones
- Elizabeth Kohlberg\*
- Laura Loftis
- Geul “Andy” Suh
- Cara Voelliger

**Fall 2013 (anticipated)**

- Nicole Jackson\*

*\*In attendance for Spring 2013 Commencement Activities*

Graduation activities were held the weekend of May 17-19, 2013. Several MSHCE graduates took part in the Graduate School Hooding Ceremony on Friday evening, the M.S. in Health Care Ethics Graduation Brunch on Saturday morning hosted by the Center, and University Commencement on Saturday afternoon.



**Graduates at Hooding Ceremony (May 2013)**

- |                                       |                      |   |
|---------------------------------------|----------------------|---|
| 1. Helen Chapple, PhD (faculty)       | 6. Annie Walker      | 11. Joe Chebuhar  |
| 2. Elizabeth Kohlberg                 | 7. Alan Heimer       | 12. Tim Cotita  |
| 3. Christy Rentmeester, PhD (faculty) | 8. Brandy Olson      | 13. Mary Homan  |
| 4. Leslie Kuhnel                      | 9. Regine Calvar     | 14. Amy Haddad, PhD<br>( <u>program</u> director/faculty) |
| 5. Nicole Jackson                     | 10. Llewellyn Powell |   |

## **Public Trust, Research, and Human Biological Material: Legal and Community Issues**

**by John R. Stone, MD, PhD**

In 2011 the Center for Health Policy and Ethics held a conference on “The Use of Human Tissue and Public Trust: The Chasm between Science and Ethics.”<sup>1</sup> The following remarks summarize two published papers that developed from speaker presentations regarding legal issues and community-based approaches in human subject research.

In “A Legal Approach To The Use Of Human Biological Materials For Research Purposes,” Marshall Kapp, JD, MPH, summarizes United States human research regulations and notes their foundation in ethical principles of beneficence, autonomy, and justice.<sup>2,3</sup> He discusses legal aspects of informed consent, privacy, and “commercial or ownership (property) interests.” Kapp also reviews arguments about “blanket” consent for not-yet-determined research studies and whether consent is needed.

Kapp writes: “within the broad boundaries set by the law’s delineation of duty, power, and limits, there is substantial opportunity and necessity for the implementation of ethical and policy discretion.” Legal boundaries “significantly influence what ethical and policy choices are made and carried out.” Of course, the legal and the ethical incompletely overlap.

Kapp also considers community harms, exploitation, and/or injustice. In deciding whether to give informed consent for research involving human biological material, individuals might consider community implications such as have followed from “studies of the genetics of sickle cell anemia among African-Americans or Tay-Sachs disease among Ashkenazi Jews.” But collective community wisdom may be needed to identify and prevent some potential community harms and injustices.

The other paper, by Claudia Hardy,<sup>4</sup> MPA, and colleagues, illustrates an important evolution in community-based research that involves community wisdom and ensures community-investigator parity throughout. Hardy presented an early version of the paper at the conference which she and co-authors then published. The title of the paper is: “Community Health Advisors as Research Partners: Utilizing Community-Based Participatory Research to Address Cancer Prevention and Control in African American Communities in the Deep South.”<sup>5</sup> The paper discusses the involvement of “community health advisors” as research partners.

The success of community health advisors (also called community health workers, navigators, and promotoras) in addressing community health has been widely reported. But the process of becoming research partners has been less frequently addressed. In the program that Hardy et al. implemented, “evidenced-based programs [were used] to improve breast, cervical, and colorectal cancer screening rates in medically underserved African-American communities in Alabama and Mississippi.”

These groups experience serious cancer disparities that flow from complex social, cultural, and economic issues. Hence, multi-dimensional responses are needed. Following the concept of community empowerment, the “Deep South” strategy involved community health advisors, other community stakeholders, and investigators in multiple partnering approaches. The main focus gradually shifted “from cancer screening to a focus on lifestyle and behavioral change.” Evidence-based programs targeted physical activity, cancer awareness outreach, nutrition through churches, and advocacy through community collective action. Significant outcomes followed.

### **Notes & References**

1. Support was provided by a grant from the U.S. Department of Health and Human Services Office of Research Integrity.
2. Kapp, M.B. (2013). A legal approach to the use of human biological materials for research purposes. *Rutgers Journal of Law & Public Policy*, 10(1), 1-29.
3. Professor Kapp is Director, Center for Innovative Collaboration in Medicine & Law, Florida State University.
4. Claudia Hardy, MPA, is the program director for the University of Alabama-Birmingham Comprehensive Cancer Center’s Deep South Network for Cancer Control.
5. Hardy, C.M., Wynn, T.A., Williams, M.S, Marron, J., & Partridge, E.E. (2012). Community health advisors as research partners: Utilizing community-based participatory research to address cancer prevention and control in African American communities in the deep south. *Journal of Healthcare, Science and the Humanities*, 2(2), 95-107.

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