REFLECTIONS

NARRATIVES of PROFESSIONAL HELPING

General Submissions
Field Education
Research Reflections
Teaching and Learning Reflections
Historical Reflections

Volume 22, Number 1 Winter 2016

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NARRATIVES of PROFESSIONAL HELPING

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REFLECTIONS

NARRATIVES of PROFESSIONAL HELPING

Volume 22 Winter 2016 Number 1

Reflections from the Editors

Michael A. Dover and Maureen O’Connor

Abstract: This serves as the Reflections from the Editors for Volume 22, Number 1 (2016), published February 2017.

Keywords: human need, social justice, injustice, empowerment, oppression, exploitation, ecosystems

February 26, 2017

It is has been a cold winter. The wonderful cover art for this Winter issue, by Art Director Robin Richesson, Professor of Art at California State University Long Beach, reflects that coldness.

For many of us, this was been one of the coldest and most frightening winters in recent memory. The period beginning with Tuesday, November 8, 2016 was a time when much went into hibernation, including this journal, which didn’t publish an issue from November 1, 2016 until the present issue, published in February 2017.

The Aftermath

Perhaps the editor was at a loss for what to say. However, soon people began to act. It became clear that something was happening. What it was wasn’t exactly clear. Everybody looked around. Battle lines were being drawn. Everybody couldn’t be wrong. Young people were starting to speak their minds. Within days, thousands were in the street, singing songs and, yes, carrying signs. It was beginning to feel familiar, like the above combination of adapted and verbatim Buffalo Springfield lyrics (Stills, 1966).

It was women, including social work women, who brought the nation to its senses and gave us hope. Even before the election, at the 2016 APM of the Council on Social Work Education in Atlanta, Ann Alvarez and her daughter Antonia Alvarez (of the University of Denver) facilitated a sing-along on Saturday November 5 (Alvarez, A. R., 2016). Michel Coconis drove from Ohio prepared, bringing drums, bells and so forth. I remember sitting there, singing along, but hoping. Hoping we would end with We Shall Overcome. Sure enough, that was the plan. We ended singing We Shall Overcome arm in arm together: “We are not afraid, we are not afraid, we are not afraid, today.” However, at one point we shifted into a revised lyric: “Oh deep in my heart, I do believe, we are not afraid, Tuesday.”

Perhaps I was hoping we would sing this because I remembered the impact which one somber rendition of We Shall Overcome song had on me after the Charleston Church Massacre at the Emanuel African Methodist Episcopal Zion church on June 17, 2015. The shootings took place right down the block from the Spoleto Music Festival, although the festival had just ended days earlier that year. Giselle Dover and I had visited the festival in 2014 to hear our son, clarinetist Mark Dover perform. The AME Zion choir regularly collaborates with the festival. The shooting prompted many musicians to become active in response, including our son. Later that month, Mark recorded a somber rendition of We Shall Overcome along with his now wife Lotte Fay and pianist Jeremy Jordan. Mark commented (Dover, M. J., 2015): “With every tragedy, we will overcome. And with every step forward as a society, let us not forget we have a long road ahead towards a just world. As musicians, we have the ability to try to move us forward with the power of song. Here's a humble attempt. Spread the love and record your own Social Justice Song! WE SHALL OVERCOME SOMEDAY.” As may become apparent in these reflections, a new generation is taking the lead in movements for social justice.

As soon as the election results were clear, several calls for the Women’s March on Washington were issued and soon consolidated. In Bloomington, Indiana, two social workers – Kathy Byers and Jean Capler – began a secret Facebook page which issued a Call for Action that attracted hundreds to participation in local and national marches (Byers, 2017). Kathy also began journaling (personal communication, used with permission). Narratives arising out of journaling, activism, practice and self-care are very welcome here at Reflections.

Here on the Cleveland State University campus, later in November, word spread among veterans: join in solidarity by coming to Standing Rock (Veterans Standing for Standing Rock, 2016). It soon because apparent that the response had been so massive, veterans were asked to find ways to express solidarity locally.

Finally, after an outpouring of activism and planning, on January 21, 2017, 3.3 million women, children and adult male supporters poured into the streets in the U.S. alone (Frostenson, 2017; Pressman & Chenoweth, 2017). In one place after another, mobilizations for the Women's March and marches and rallies for refugees and sanctuary were initiated by a new generation of emerging activists and by a solid contingent of re-activists (those who are returning to activism with their accumulated wisdom).

This activism began to bring people together. We learned that social worker and Cleveland State University alumna Bridget Crist is a leader of Showing Up for Racial Justice (SURJ, 2017), a local chapter of the national organization of the same name. On the Cleveland State University faculty, Patricia Stoddard-Dare returned from the Women's March on Washington, which she attended with her entire family, with a message that social workers needed to be in solidarity with this and other movements for social justice.

These emerging activists, longstanding activists, and re-activists are what the late social work activist Verne Weed used to call *live wires*. They are showing their ability to follow Verne's advice to be *political* rather than *politicized,* an occasional bad habit of many activists (perhaps the editor included). When one is in doubt about how to proceed, it behooves one to follow the initiatives of others.

From Letter to Reflections

By now you may have realized that this is the narrative voice of the editor, the first author of these reflections. I am speaking in my personal voice and in my professional capacity as editor of this journal of narratives, not in any other capacity. Each of the previous editors would also comment upon the issues of the day when the times demanded it. Sonia Leib Abels was the founding editor and served from 1995 to 1999 Volume 5(2). Her successor Jillian Jimenez at first called her editorial introductions Reflections from the Editors, a practice restored with the present volume. Tragically, her last issue as editor was 2009 Volume 15(3). Following her death from a sudden and aggressive form of cancer in October 2009, the institutional strength of the journal's following asserted itself. Rebecca Lopez, Associate Editor, stepped in to oversee 15(4), which contained several of the final manuscripts overseen by Jillian, including my first submission (Dover, 2009). Three special issues followed, with the last of the three being a Special Issue on Social Justice in the 2010 Volume 16(3). That issue honored Jillian. Paul and Sonia Abels discussed her many contributions. The legacy of Sonia and the untimely death of Jillian were also discussed in the Letter from the Editor from Eileen Mayers Pasztor, Jillian's successor beginning with 2010 Volume 16(4). Yours truly succeeded Eileen as editor in 2012 Volume 18(2).

These are not times to remain silent, neither for the editor nor for our readers, reviewers and authors. A dated introduction from the editor – especially in an online journal – has the capacity to address in a timely manner those issues that are urgent in the world around us. These are the very same issues that surely influence the nature of the work we are doing with clients and in communities. Thus, they are relevant for a journal of reflections on practice.

Call for Narratives

Accordingly, after consulting with the Editorial Team (please see About, Editorial Team at www.rnoph.org), the journal is calling for general submissions which are narratives about the personal, professional and political impact the election of President Donald Trump has had on our personal, professional and political lives and has begun to have on our clients and communities. In particular, narratives are sought about participation in the growing social and political action of social workers and other helping professionals, in our capacities either with our employing organizations or as private persons.

We are also open to proposals for a special section along these lines. Please see the Call for Narratives for Special Themed Sections on our home page. A similar call from this editor in 2014 – following the advent of the Black Lives Matter movement – lead to the publication of the Special Issue on Dismantling Social and Racial Injustice, edited by Sadye Logan and Priscilla Gibson and published in June 2016. That issue is must reading as we head into the coming period. Please see Archives at the website.

News from Reflections

In this issue, the manuscripts were all written earlier, much earlier in many cases, as this journal and its staff have gradually learned the art of editing and the details of publishing this wonderful journal. As the editor has learned since May 2012, serving as one of the editors of this journal or as one of our over 100 reviewers requires a great of emotional labor.

The manuscripts are often moving or even disturbing. They require an open heart and mind for the readers as well. However, the publishing tasks of the journal (from fund raising to website maintenance to copy editing and proofreaders) are also very demanding. Ideally, two different persons should oversee these roles. Plans are now underway to ensure this is the case, while ensuring the next editor full editorial independence.

This is the first dated editorial introduction, as Reflections from the Editors. This practice will continued until the Journal is fully up to date in its publishing schedule, as is planned for Summer 2017. Significantly, the publishing of the journal is now supported by several schools of social work, who have formally agreed to or pledged to become Publishing Partners and provide annual financial or in-kind support to the journal. Publishing Partner schools of social work typically have an established base of *Reflections* authors and/or reviewers. A representative of each of these schools will serve on an Executive Committee, chaired by Cathleen Lewandowski, Director of the Cleveland State University School of Social Work.

Announcements about this will be made in the months to come. But what can be announced now, one year since the journal announced in January 2016 that it was taking the risk of ending individual and library subscriptions and becoming open access, is that over 330,00 views of our abstracts have taken place in one year. Also, there have been 180,000 downloads of PDFs of our articles or full issues. These aren't just clicks. They as they require the actual opening of a PDF file.

This is good news for the long-term survival of the journal and its goal of remaining a high quality, double-blind two-peer review open-access journal for many years to come. However, the journal also needs the support of Friends of Reflections, over 60 of whom have donated nearly $10,000 to the journal. Please see information on the website and consider supporting this journal. We don't charge authors. We don't charge readers. We don't charge libraries. But we need your support.

The Narratives in this Issue

This Letter from the Editors is co-authored by our 2nd year MSW student Graduate Assistant Maureen O'Connor, who has ably summarized each of the following manuscripts. She has provided valuable feedback since she arrived in August 2015. Maureen has also played an important role working together with Kailie Johnson, BSW-Candidate, now in her third year with the journal as Editorial Associate, and Elisabeth Weems, BA-Candidate, Journalism and Promotional Communications, Cleveland State University, our Copy Editor.

In this issue, in a submission to the Field Education Section, edited by Beth Lewis of Bryn Mawr College, Wendy Ashley, Sandra Santracruz-Cervantes and Tina Karnsomprot Castro collaborate in a narrative that shares their experience encountering professional conflict in a social work academic and field setting. The main writers are a seasoned field supervisor and faculty member, and a graduate social work student. They are part of a transdisciplinary team that is providing treatment to a family that is raising a child with Autism. As the only women of color on the transdisciplinary team, they cite research about how female social workers who are persons of color continue to experience prejudice and racism in the work place. They explore finding their competency questioned in much the same way that the literature outlines. While white men disproportionally advance in the hierarchies that exist in even the social work fields, women of color, including those in academia, continue to struggle to be perceived as competent by their white counterparts. These authors are candid with the racism they encounter. They remind us of the work that is still required of us in eradicating systemic racism and hierarchy, even in higher education and social work.

In the first of two submissions to the Research Reflections Section, edited by Julie Altman of California State University Monterrey, Jennifer C. Hughes, in "Care by the Caregiver" addresses the need for self care for caregivers, specifically those who care for a person diagnosed with Multiple Sclerosis. Inspired by her experience as a caregiver to her husband, she decides to conduct a qualitative research study on how MS affects people in a caregiver/care recipient relationship. Hughes carries out interviews with 20 participants, each either a caregiver or recipient diagnosed with MS. She finds that disclosing her own experience caring for her husband allows her participants to open to her in ways that might not have, without knowing her family had also been affected by MS. These interviews are often in depth. They provide great detail to the profound ways MS affects the lives of each couple. Hughes finds that she has her own emotional reaction after hearing her participants stories. She uses journaling to process her own feeling. From her interviews as well as her own journaling process, Hughes extracts common themes that run throughout every caregiver's story. Hughes notes that treatment is most often focused on the patient with MS rather than the caregivers but emphasizes the importance of caregivers to receive care and attention for their own social and emotional needs. Of the many themes she finds from her interviews, an important one is that caregivers often struggle with acknowledging their own needs and receiving help, since they are usually so focused on the need of their loved one. Hughes' narrative offers a compelling rationale for continued research and resources to foster the emotional and physical wellbeing of our caregivers, so that they can continue to provide important care to their loved one, or client.

In the next Research Reflections narrative, Christopher Cotten, in "My Cisgender Comeuppance," writes about the continued practice of social workers, and society in general, to remain aware of one's privilege. As a white gay male, Cotten acknowledges he is both a member of a marginalized group as well as a traditionally privileged one. He is hired to work on curriculum for an HIV-prevention program with two other authors, one white trans woman, and one African American transgender woman. Aware of his privilege as a white male, Cotten works hard to establish trust and positive rapport with these women and the three are successful in creating effective curriculum for an HIV-prevention program. Despite his efforts not to use his privilege to monopolize his agenda over the other two writers, he finds that he commits a faux pas with his colleagues. Cotten's story is a reminder that as allies, we will still make mistakes when working with our colleagues who are also members of traditionally oppressed and marginalized groups. However, it is in our willingness to face our flaws, acknowledge our privilege, and try again, that perhaps, over time, will weaken the structures that reinforce these oppressive patterns.

In a submission to Teaching and Learning Reflections, edited by Arlene Reilly-Sandoval and Carol L. Langer, of Colorado State University Pueblo, Larry Owens write about working as a social worker before entering the world of academia, Owens finds that although he is highly knowledgeable after years of clinical work and then working as a director and administrator, he finds striking differences between the practice of social work, and in academia. In "Reflections of a Pracademic: A Journey from Social Work Practitioner to Academic," Owens, now a full time professor of social work, notes that this change brought a period of transition for him, as he adapted to the differences between the two settings. Owens describes his process of learning the unwritten and written rules of navigating within an academic setting, and how he worked to adapt to this new setting. Owens offers guidance and encouragement to others thinking of transitioning from the "practice" of social work to an "pracademic," noting that this risk he took, although uncomfortable at first, ultimately allowed his skills to shine and enabled him to bring unique perspectives to his university. Transferrable skills to the classroom allowed him to give his students a unique perspective

In a general submission, Dana Davis and Patricia Park collaborate in "That's What a Social Worker Does" to describe a challenge that many adults will in their life time, that of caring for a sick and aging parent. However, they offer important information as they experience on the other end of the social work they usually give in the hospital. Davis and Park, both social workers, write of the struggles they faced in attempting to solicit social work support for their own loved one, in a medical setting. They write: "Social workers are the one group that should rise above the system and provide empathy, caring and supports”. However, they find in their respective experiences that this was often not the case as they interacted with hospital staff. Certainly the medical model poses challenges for upholding the tenets of social work, and both Davis and Park offer an important reflection of this dynamic as recipients of social work in a hospital setting.

In a general submission, Raymie Harvard Wayne, Christine Limone and Stephen A Karp collaborate to detail their accomplishment of changing hiring requirements for social work positions. As members of the NASW, their charge was to improve the hiring practices of state agencies, such as child welfare agencies, so that the clients of these agencies would be served by professionally degreed social workers. Drawing on research that shows a social work degree improves retention and service delivery to clients, they began the steps to reach out to local and state officials, to bring this issue to awareness. Encountering some resistance however, they discover that many of these same officials do not view the role of a social worker as serious enough to require a social work degree. They persevere through various levels of bureaucracy until the Lieutenant Governor agrees to mandate that state agencies show preference to degreed social workers over applicants with degrees in other disciplines. Their fight to have the social work degree considered a real and serious degree draws on many macro skills as they engage with multiple governmental bodies, collaborate with unions, strategize, and recruit letters of support from other agencies. They share how each of their strengths gave them important roles in working collectively and also collaborating with legislators.

In a general submission, Carol Weissmann Mauck addresses the highly relevant issue of a large aging population. She draws on her extensive experience as a owner and founder of an adult day care for the geriatric population. Although Mauck opens this center to provide a much needed resource for aging adults and their families, she finds unexpected challenges and dynamics with interacting with the care giving relatives of her “clients,” as well as in caring for the actual “clients,” such as an aging adult with dementia. Some challenges include caring for clients whose native language is not English, leaving them often confused and frustrated in adapting to a day care program. She explores the decision making processes of caregivers, in deciding to use a day care program for their aging parent, often so that they could get rest and exercise in order to continue caring for their loved one. Mauck notes this can difficult for adult children, who often feel guilty in leaving their loved one in a day program. At times they have to adopt a “tough love” approach to sending their family member to the day program, so that they can get some rest. Mauck identifies the need for more research into how a day care program can assist older adults with aging in place, as well as how they adjust in such programs, and how day activities can enhance their experience.

In another general submission, Gayle Mallinger and Molly Kerby discuss the growth of locally produced organic food in the United States, and the role of farmers markets, community and school-based gardens, as well as campaigns to promote the consumption of vegetables by children and adolescents. As they both show and tell, local communities are increasingly recognizing that disparities exist in poor neighborhoods, with respect to access to fresh produce, education, and food programs. Their article portrays the role of a community garden project at a Boys & Girls Club in Kentucky, over a three year period.

The final narrative contributes to the Historical Reflections section. John Tropman and Emily Nicklett collaborate on discussion of a project involving noted sociologist Talcott Parsons. Talcott Parsons, a notable sociologist of the twentieth century was a scholar who utilized the theoretical perspective known as structural functionalism. Parsons’ work focused on social action, the structure of values and how they impact one another, as well as shape society. His work also studied the relationship between health systems and society, visualizing the healthcare system as one that works to supply society with an efficient and healthy workforce. These authors, with backgrounds in management and leadership, and aging and health, found that Parson’s work, specifically his Adaptation, Goal Attainment, Integration and Latency (AGIL) Theory was very applicable to their fields. They note how Parson’s emphasis on the need for an external “disruptive force” is necessary to initiate change within a system. Both writers lament the passing of Parsons, and speculate to how he might have influenced students today. As social workers, we can learn a lot about the oppressions we are working to influence by looking at how a larger system perpetuates the imbalances we work to correct.

Theorizing in Reflections?

The article by Tropman and Nicklett is consistent with the intent of the Historical Reflections section, which often has autobiographical or third-person accounts of important historical developments in the helping professions. But theirs is also a narrative about the process of theoretical debate and development itself. Narratives submitted to our Research Reflections section, edited by Julie Altman, can also include accounts of the process of theorizing that accompanies the process of the research portrayed.

Nevertheless, it has not been often that narratives in this journal reflect upon theory and theorizing, although our Call for Narratives, including general submissions, certainly encourages this. True, *Reflections* narratives probably shouldn't stray into long theoretical discussions, in a way that promotes the cognitive over the affective. But isn't theory the outcome of a process of theorizing? Isn't theory about asking questions? Isn't theory about solving conceptual and empirical problems? And isn't this something which comes out of our interactions with other people in the process of doing our research, working with our clients, talking with students, and debating with colleagues about the conceptual problems we face?

The notion that theorizing is a process – even a craft – is one that has recently been stressed by Richard Swedberg, starting with a 2010 call for papers on the craft of theorizing (Swedberg, 2010, 2012, 2014a, 2014b). Narratives reflecting on the process of theorizing about our practice are particularly important for the present era. They are certainly welcome in this journal. In reflecting on our practice, it is important for us to re-think the theories which undergird our practice. Those theories are often mainly implicit. Often, they reflect tacit knowledge and practice wisdom, and that is important. But arguably our theory base is overly eclectic.

As David Tucker (1996) has pointed out, eclecticism is not a free good. Perhaps we don't fully recognize the opportunity costs of our not prioritizing our theoretical perspectives, whether they be the empowerment tradition in social work practice, the ecosystems perspective, or theories of oppression and social injustice. One important conceptual step towards a re-examination of the theoretical foundation of social work was recently made by Mimi Abramovitz and Margaret Sherraden (2016).

One contribution to this discourse, rooted in the narrative style of this journal, will be seen with the publication of the Special Issue on The Interconnections of Micro and Macro Practice, to appear in summer 2017, edited by Darlyne Bailey and Melissa Emerson of Bryn Mawr College Graduate School of Social Work and Social Research. Another contribution has been made by two Reflections contributors, Michael Reisch and Charles Garvin, authors of the new book *Social Work and Social Justice: Concepts, Challenges and Strategies* (Reisch and Garvin, 2016).

The need to clarify the nature of social justice and injustice is reinforced by the observation that it is undeniable that Supreme Court nominee Neil Gorsuch, holder of a Ph.D. in Law (Legal Philosophy) from Oxford, has his own developed conceptualization of social justice. We should not assume that those who think differently than most helping professionals do not have a plausible or even legitimate outlook on social justice.

We can, however, seek to ensure that our own view of social justice is even better conceptualized. On what conceptualization should our theory of justice rest? In this journal, David Gil argued that any theory of justice requires a conceptualization of human need (2004, p. 32-33):

> Many advocates of social justice tend not to specify their understanding of this concept. They act as if its meaning was self-evident and, therefore, did not require interpretation. When challenged to specify the meaning of the concept, they tend to hesitate. Leaving the meaning of social justice unspecified may actually be quite useful, for the vagueness of the concept enables people to avoid facing the implications of a clear definition for their accustomed ways of life.....On the level of social institutions and values, social justice means

> socially established living conditions and ways of life that are conducive to the fulfillment of everyone's intrinsic needs and to the realization of everyone's innate potential, from local to global levels. Innate human capacities tend to unfold spontaneously when people have opportunities to fulfill their intrinsic needs in their natural and social-cultural environments.

In his comments upon receiving the Noam Chomsky Award from the Justice Studies Association, Gil (2008) further contended that we must focus our attention on addressing human needs, as we go about pursuing global social justice. The needs-based ethicist Gillian Brock has make exactly that point (Brock, 2009). Also within philosophy, David Wiggins (1998), clarified the distinction between wants and needs, differentiated absolute and instrumental needs, and contended that there are identifiable, objective, non-circumstantial conditions which are required in order to avoid serious harm. Wiggins explicitly criticized theories of justice that don't draw upon a clear conception of need (2005).

Since Gil and Wiggins wrote, the Council on Social Work Education's 2015 standards (CSWE, 2015) now require that our schools teach about "knowledge of theories of human need and social justice." In this political environment, we need to better anchor our advocacy for social justice and our intersectional resistance against injustice in our articulation of human rights and human needs.

Human needs have been a marginalized component of social work discourse since the destruction of the plates of Charlotte Towle's *Common Human Needs* by the federal government, at the height of the McCarthy period (Posner, 1995). Although the book was later reprinted by NASW (Towle, 1957), only recently have overviews and critiques of theory of human been published in the field of social work (Dover & Joseph, 2008; Dover, 2016a; Jani & Reisch, 2011). However, the concept of human needs is increasingly being found in the demands placed by emerging social movements. This has been the case since the Occupy movement, when "Human Needs Not Corporate Greed" emerged as one of the most frequent slogans. This is portrayed in the following photograph taken by the editor in downtown Cleveland in October 2011:

Addressing Human Needs

In the present environment, helping professionals are well positioned to point to the reality of the unmet needs of our clients and communities. A good example of taking seriously the content on addressing human needs in the NASW Code of Ethics is the recent document prepared by the National Association of Social Workers for President Trump's administration (NASW, 1996, 2017). On February 23, 2017, that document was used to inform an effort by a group of macro social work activists including Kristin Battista-Frazee; Laurel Hitchcock; Stephen Cummings; Sunya Folayan; Pat Shelly; Rachel L. West; Vilissa Thompson, and Karen Zgoda, and the Association for Community Organization and Social Administration (ACOSA). They issued a Open Invitation to the Trump Administration to Engage the Social Work Community via a #MacroSW twitter chat, and have made available the archive (#MacroSW, 2017).

Just last week, local social worker Molly Brudnick was one of those who spoke out at a Town Hall meeting held by Congresswoman Marsha Fudge. According to Molly (personal communication, February 25, 2017):

> The turn-out was HUGE! Many people of color, all ages. Probably over one thousand people. More than one line – up the full length of the hall – to

> speak! Moving statements – one man crying about his neighbor's health care issues and needs. There were staff people from Congresswoman Fudge's office with whom the Congresswoman connected speakers to help them with their issues....A nurse from Metro Health spoke to the help Medicaid provides for adolescents. An immigrant got such great support with everyone standing with him, who could stand, and another person with a question telling the man we are all immigrants.....I stepped up and said that we all know what the problems are – including hate, anti-Semitism, anti-ObamaCare – but what actions will Congresswoman Fudge and her Congressional colleagues take together? She said that they stand together against President Trump's unqualified appointments. She also said that we should look to see their action when next the President speaks.

Also last week, social worker Bridget Crist spoke on behalf of Standing up for Racial Justice (SURJ, 2017) at the City Club of Cleveland, prior to the presentation of Eddie S. Glaude, Jr, Ph.D. of Princeton University (Glaude, 2017). Glaude shouted out to Bridget several times as part of making one of his key points. This point concerned one important lesson of the civil rights movement: namely the need to organize in our own backyards. Bridget is organizing white folk to fight racism. Others are organizing in the social work backyard.

For instance, on March 16, 2017, here in Cleveland, the 7th Annual Cuyahoga County Conference on Social Welfare – coordinated by Lori Longs-Painter of the Jack, Joseph and Morton Mandel School of Applied Social Sciences at Case Western Reserve University – will be meeting on the theme *What Happens When Everything Changes* (CCCOSW, 2017). The planning of a morning plenary and workshop at the conference on the topic *In Solidarity: Building Intersectional Resistance* has been inspired by the very emerging activists, consistent activists, and re-activists discussed above, as well as by the dedicated Ohio NASW chapter staff, including Danielle Smith, Dorothy Martindale, and Colleen Dempsey. Bridget will be among the speakers at the plenary session, and the workshop will be moderated by CSU faculty member and field instructor Joann Hall and by CSU alumna Katy Carpenter. As we prepare for this event, a CSU MSW student made a valuable comment discussed in class and valuable to share here (Artie Bruce, BSW, MSW-Candidate, used with permission): "As social workers we should not be satisfied with the status quo. As social workers we can make a difference if we make our voices known. I have always been told, 'A closed mouth can't get fed.' We must speak and speak loudly. Change can begin with us." This made me think: why can't helping professionals take the lead in initiating social struggles? We have the diversity and lived experience and moral authority to initiate new coalitions and formations, as was the case during the Progressive Era.

Praxis of Sorts

As these examples show, social workers along with our allies are in action advocating for social justice. As social workers and helping professionals, we have an ethical commitment not to discriminate on the basis of political beliefs with our clients and colleagues. We have many varying views. However, by strengthening our theorization of human need and applying that theory to a re-conceptualization of social justice and social injustice, we can strengthen our common understanding. Perhaps by linking empowerment theory, ecosystems theory, theories of oppression and social injustice, and theory of human need (Brock, 2009; Miller, 2012; Gough, 2015; Ryan and Deci, 2017), we can be more effective as helping professionals and more persuasive in our social and political action.

We can enhance our effectiveness if we understand what it is that happens at the intersection of the individual and the social environment. It is at the moment of that intersection that people experience either opportunities or barriers to addressing our human needs (Dover, 2016b). Injustice, in other words, is produced by the manner in which oppression, dehumanization and exploitation produce social mechanisms that can create systematic inequality in our opportunities to address our needs, leading to unmet needs and serious harm. Our activism is addressed to removing the causes of systematic inequality, dismantling the barriers to addressing needs, and addressing the cumulative historical consequences of these unjust barriers. Our activism seeks to establish and enforce human rights of the kind necessary for achieving social justice.

It is one thing for us to repeat these lyrics to those who aren't listening (Dylan, 1965): "Because something is happening here, but you don't know what it is, do you, Mister Jones?" It is another thing for us to speak real truth to power: truth about the reality of the unmet needs of our clients, of our communities, and of people the world over. Something is in fact happening here. We can be an important part of it if we act, speak out, and write narratives of our experiences than encourage others to act as well.

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Professional Conflict in Social Worker Development: Transdisciplinary Challenges for Women of Color

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Abstract: Field instruction is the signature pedagogy of most Masters of Social Work graduate programs. It provides students with the context to practice and integrate academic material they have studied in the classroom. It is a core belief that field experience offers opportunities for professional growth and development. Students are encouraged to re-frame difficult experiences and conflict as a challenge to expand their professional lens. However, the role of conflict among professionals throughout the collaborative process may impact women of color differently. The racial and gender imbalances in social work education and the service sector can be disheartening. Navigating the differences between professional conflict and systemic silencing based on color and gender lines is a life lesson for many students of color that is not addressed in MSW classrooms. These narratives focus on the different perspectives of female social workers of color at different levels: a seasoned, licensed supervisor and a first year MSW student grapple with conflict and attempt to collaborate effectively with professionals from various disciplines. The narratives explore the challenges inherent in navigating within a transdisciplinary team and coming to terms with questions that spring from systemic, racial and gender inequality.

Keywords: transdisciplinary team collaboration, social work field instruction, racial and gender inequality

Introduction

Field instruction provides social work students with the context to practice and integrate the academic material they acquire in their courses. Fieldwork offers the unique opportunity to analyze and re-frame challenging experiences, learn interpersonal skills and inform future professional judgment. Social workers frequently work in settings that utilize interdisciplinary, multidisciplinary and transdisciplinary models. Holistic transdisciplinary models benefit clients and enhance student learning, but must include consideration of the nuances of the culture, climate and disciplines involved, and the ecology of higher education (Vanasupa, et al, 2012). The rules, boundaries and collaboration regarding the *process* of transdisciplinary intervention directly impact efficacy and are often riddled with conflict.

Acquiring skills to manage conflict and address social injustice is a multifaceted process essential to social work that may impact women of color differently. The following narrative includes the commentary of two women of color on a transdisciplinary team coping with professional conflict, and the impact it has on their social work identity. Narrativizing personal experiences is the epistemological process of meaning making (Munro, 1998), which affords marginalized individuals empowerment and voice. Because narratives are methods of communicating real, lived experiences, these individual struggles may reflect some of the larger, invisible barriers facing female social workers of color.

Field Instructor/Seasoned Social Worker Commentary

Teaching at the graduate level has consistently been a source of ambivalence for me; my passion comes from my love for social work and my elation is due to the influence and power of academia, but I have the fear of being classified as incompetent due to my status as an African American woman in a white male-dominated institution. When my social work department chair asked me to take the lead in providing supervision and clinical support for the newly formed multi-disciplinary autism group on campus, I felt a sense of pride and competency for having been selected. As a seasoned social worker with over 20 years of practical experience, I have spent the majority of my career working with children and families. My social work role in the project would be to provide case management services to families with one or more children diagnosed with an autism spectrum disorder. This project would also provide valuable experience for social work students who would serve as the hub of the university-based program.

This particular project was touted as being transdisciplinary. This is in comparison to the typical interdisciplinary approach which involves multiple branches of knowledge sharing varied perspectives of problems and solutions. The transdisciplinary approach transcends disciplinary boundaries to holistically address clients' needs. The success of the project hinged on the collaborative relationship between the core team members, all who were from different disciplines and had diverse experiences and skills, but all specialized in autism spectrum disorder services. We established a monthly team meeting to discuss cases. Upon sitting down for the first meeting, I quickly realized that my student and I were the only people of color at the table. I brushed off this reaction because it wasn't the first time this had happened. This time, I was coming into the situation as an experienced professional, a supervisor and a junior faculty member. I focused on my excitement. The project felt like it was blossoming into an exciting and innovative prospect wherein we would all gain insight into each other's expertise.

The tone of the meetings gradually changed as our caseloads grew. What once felt like collaboration and support became tense and uncomfortable, with one person dominating the discussion and my feelings being effectively silenced. Service delivery was within my scope of competence, but when I attempted to assert my perspective or support the student in meetings, he would minimize my comments or argue that my feedback was erroneous. I wondered if he felt threatened. I started coming to the meetings anxiously anticipating when it would happen and would leave with a knot in my stomach. I slowly began to resent this opportunity. The vision of a supportive meeting of the minds was shriveling into an oppressive burden of orders and ego.

One particular meeting, I left about 15 minutes early for another appointment. This meeting felt productive, and my student presented her cases and received support and positive feedback from the team. I felt a tentative relief that maybe things were changing and that the team was finally developing some cohesion. My precarious optimism abruptly popped like a balloon by the meeting needle later that evening. I checked my emails and realized I had about 20 new messages from the team and several voicemails from my student. I found that a few moments after walking out the door, several questions were raised about whether a child abuse report was warranted in one of the student's cases. The emails were the product of an ongoing dialogue between the team members, filled with directions for the student and me.

I felt blindsided by the onslaught of dialogue. I was suspicious as to why this didn't come up while I was present during the meeting, and furious that none of my colleagues sought my input. Rather, they shot off orders. As a social worker with significant child welfare experience, I have a clear understanding of state-mandated reporting responsibilities and in my opinion, this situation did not require such extensive dialogue. In an effort to decrease everyone's stress levels, I reviewed the emails and quickly sent off an email to the group informing them that I would directly address the safety concerns, and reminded the team of my extensive child welfare experience. I also called my student to instruct her regarding Department of Children and Family Services (DCFS) case consultation.

However, the frantic conversations continued and grew to include a number of people outside the team: campus police, the university risk management department and colleagues from multiple departments. I felt that my years of experience and recommendations were ignored by my teammates in lieu of others who seemed to have little insight into this case. My professional pride was bruised and my personal self was hurt and enraged. Painful questions surfaced in the back of my mind. I wondered if I my expertise was viewed as insignificant next to my white counterparts. While I knew I was the most competent one on the team to address these concerns, it seemed that the team didn't realize or respect that. I tried to rationalize that they were ignorant regarding the role of social workers, but their outright dismissal of my input gnawed at me.

I also struggled with concerns about the family and the project. Our families signed consents to allow us to share their personal information with our collaborative team members. Breaking confidentiality is a serious, ethical quandary and requires reflective dialogue and team support. I knew my colleagues were trying to act under the best of intentions because they were concerned about a client's safety, but their lack of insight caused them to act preemptively. The 'what ifs' swirled through my head. The team was committing a grossly unethical violation of privacy and was leaving us vulnerable to legal repercussions. Of course, had they thought to consult with me, they would have known that.

I kept returning to the awareness that I was the only faculty member of color involved since the onset of the project. As an African American, female junior faculty member, I am sensitive about how others perceive me in an environment that consists primarily of white men and women. For my student, a woman of color, to see me disregarded and ignored by senior, white faculty members made me feel incredibly ashamed and humiliated. Feeling defeated and no longer willing to be silenced, I decided to resign from the project. I forwarded all the emails to my department chair, preparing her. Then I met with her to give program documents and a tentative plan to hand off the project to another faculty member. I reminded her of the electronic exchanges between the team members, highlighting how disrespected, minimized and incompetent I felt in relation to the team's decision making process. Awkwardly, I tried to explain to my white department chair how the consistently unpleasant group exchanges, which culminated into the disparaging campus-wide discussion that excluded me, felt like a microinvalidation of both my supervisory and clinical skills and a microaggression towards my student and the client system. Because she was familiar with the more difficult group members, I anticipated she would understand my distress, be disgusted by the disrespect to the discipline and transfer the project to protect me from further injury.

However, instead of accepting my resignation, she reached out to the other team members and arranged a meeting. I was surprised to find a small part of me felt grateful, despite a looming sense of skepticism and hesitation. This felt like a critical juncture; it was likely that I could continue to be invalidated and devalued. I was afraid of the shame that would follow and pained to face the ego assault it may have invoked. Despite my years of education, tedious professional growth and my passion for both my field and students, one reality remained inescapable: I am still a Black woman standing before a white man demanding to be taken seriously. Knowing I could so easily be dismissed burned a very essential part of me. Why should I trust a group of people who blatantly ignored my voice?

The juncture could, however, take an optimistic turn; perhaps the meeting might yield a mutual understanding of minds. But mostly, I refused to allow the group to silence me or remember me as a quitter, and that is what motivated me from then onward. I forced myself to sit with the core team members and explained how I felt mistreated and invalidated by the recent exchanges. I highlighted my concerns about my role as a Black woman supervising and educating clinicians of color within this context. I braced myself, expecting ignorance and defensiveness. To my surprise, we were able to talk honestly and openly about the incident from each of our perspectives and strategize how to avoid similar incidents in the future. The meeting focused primarily on content, discussing our problem-solving methods, conflict resolution expectations, supervision protocol, and legal and ethical responsibilities according to our differing disciplines. Following the recommendation of one of the team members, we decided that I would address any remaining concerns with the students in supervision. We agreed that a large part of this conflict was standard internal challenge–differing world views and experience that lead to miscommunication. I walked away from the meeting feeling essentially validated and heard. But later, a teeny part of me wondered why the resolution with the students had to be done privately. If the microaggressions occurred within the group, why did the responsibility of recovery fall on those feeling victimized by the exchange? And why had I agreed to this strategy? I couldn't escape feeling that although we resolved the content of the issue, the process was never fully addressed. Despite being the most skilled person in the room, I was presumed incompetent. Retrospectively, I struggle to identify anything other than gendered racism as the culprit.

Lastly, I worried that my student would ultimately remember how I was ignored and wondered if that experience demeaned my credibility with her. As a young woman of color entering the field, I wanted her to see how the social work values of collaboration, competence and confidentiality help keep us grounded in times of discomfort. I fear that the student saw a different struggle than I intended–one of tension, fear and silence. My most prominent hope is that the student has learned through watching this process that her voice matters. Discrimination and silencing can be infuriatingly ambiguous, but we can still thrive. I hope to set an example for women of color so that they can feel confident in leadership roles and can maintain strong collaborative relationships. If I only had to manage some discomfort, perhaps the experience was worthwhile.

Student Perspective

Although I was green to the social work field at the time of my first internship, my prior experience in working with children with disabilities provided me with an understanding of the importance of collaboration. I was confident coming to a meeting table of transdisciplinary colleagues and held an exciting vision of this project. However, I also anticipated being pushed to the periphery due to my status as intern. Although I was excited, I worried whether my contributions would fall on deaf ears.

While sitting in on the first transdisciplinary team meeting, I observed the dynamics of professionals and was able to get a sense of what each had to contribute as well as the amount of symbolic space each occupied. As a woman of color, I have witnessed “space” being discussed ad nauseam. Many bemoan the lack of women of color across multiple settings, but are hesitant to address discrimination and silencing within their own realms.

I was assigned multiple cases, and one involved a family of six. Their 12-year-old child was diagnosed with severe autism and exhibited behavioral problems that caused great burden and frustration for the family. After meeting with the family, an internal drive to bring them support and relief began to brighten within me. I worked with my supervisor to develop goals and was excited to propose an intervention plan at the collaborative meeting.

I hoped to paint a picture of an exhausted family, desperate for guidance on how to meet their son’s needs and to rally my colleagues into beautiful, empowering and collaborative action. The reality of clunky collaboration and compromise soon made itself clear, particularly when the risk and liability arose. I introduced one of the many complex issues that stressed this family: the son with autism had to be the first one to enter the family vehicle and did not allow anyone, including himself, to wear a seatbelt. If there was any disruption to his routine, severe tantrums ensued.

I attempted to explain the mother’s concerns: she loved her family and knew this was unsafe; a routine trip to school was transformed into a storm of guilt and fear. She was at a loss of what to do and came to us for help. However, my colleagues stopped hearing me and the group erupted into a cacophony of noise. The group members began talking discordantly to me and to one another and the collective anxiety skyrocketed.

What started as a simple report on a behavioral concern escalated into a circus. I was bombarded with a plethora of questions, commands and suggestions. I felt vulnerable and uncomfortable. The group members strongly felt that the parent was endangering her children. They demanded to know her plans in addressing this safety-related issue and offered multiple recommendations regarding what my initial and subsequent steps should be. None of them involved following up with the family.

I felt incompetent. I had no easy solution. I met with my supervisor and, utilizing her broad experience, we carefully crafted some intervention possibilities that respected both safety and the needs of the family. However, it was ignored. It seemed that everyone had a suggestion and was uninterested in the social work perspective. My training has emphasized that social workers do not make decisions without considering context. This mother knew that allowing her son to dominate the family this way was unacceptable but was in a bind. She could not physically restrain her son and force him into a seatbelt, nor could she demand his siblings do so. She could not safely drive with preteen tantrums in the car, nor could she shirk daily tasks. Social workers take in every minute dimension like these and work with clients to collaboratively develop a plan that will address their concerns. This pivotal element is what makes or breaks a therapeutic alliance. The team was asking me to take away the family’s agency, disregard the complexity of the situation, and effectively tell them “you are not competent enough and we need to fix your problem for you.” The only outcome this would accomplish is to make the mother feel more alienated and hopeless. Feelings of resentment began to fester. I felt betrayed and abandoned because they were comfortable making a decision that would corrupt my alliance with a family.

The outcome of the meeting was underwhelming. When it ended, the team decided to take a break from the matter and reconvene. We left, but the discussion continued without input from me or my supervisor. I never heard back from the team about this issue. It seemed like subsequent decisions were made behind closed doors. The next week, my supervisor helped me find some resources for the family. Under her guidance, I resumed my work with them. It almost seemed like the violent disruption never occurred.

This experience redefined collaboration for me. I will enter the professional sphere with anxiety about several prospects, including being ignored, silenced and overrun. Looking back on that day, I feel that as a transdisciplinary team, we potentially did a disservice to the family by not considering their perspective. Collaboration was more stressful than helpful and I was forced to navigate a series of professional personalities as well as those of the family. The purpose of a transdisciplinary model is to ensure that clients have the benefit of experts in multiple fields to provide a thorough analysis of their concerns, insight regarding their needs and a shared common goal. Unfortunately, when power dynamics and proclaimed experts cannibalize self-determination, there is no room for true social work to occur.

I have learned to carefully consider my audience when divulging confidential details about my clients. If I am unconvinced of the team's scope and practice, I am cautious and much more apt to turn to a fellow social worker. My training has yielded a certain comfort and for the most part, I trust only my colleagues to consider the complexity of a client's system. Although this compromises the transdisciplinary model, I am comforted by the fact that I will not have to relive this situation.

Discussion

Social work students are frequently placed and ultimately employed within multidisciplinary settings. Although these settings offer opportunities for enhanced treatment coordination, discrepancies in discipline, language and pedagogy create challenges for effective collaboration within interprofessional research and practice. Transdisciplinary models move beyond coordination and collaboration, reflect shared, integrative frameworks, and emphasize the contextual frameworks of both professionals and clients (Bellamy, et al, 2013). Despite the appeal of the more holistic transdisciplinary approach, research has illuminated the need for caution regarding the focus on student learning or client benefits without serious consideration of how faculty and institutions are organized to support differentiated disciplines (Vanasupa, et al, 2012). Within institutions of higher learning, differences in discipline culture, hierarchies related to positionality, and individualized intersectionality factors provide a foundation for inherent challenges within transdisciplinary groups.

In transdisciplinary academic collaborations, women of color may face additional challenges due to their status as double minorities. Despite contemporary efforts to respect diversity, academia continues to uphold traditional hierarchies that reinforce systemic oppression. Some researchers argue that women of color face challenges that are a result of a historically gendered and racially biased academy (Kelly & McCann, 2014).

These narratives represent female social workers with varied social identities working collaboratively to utilize the transdisciplinary model. Consistent with the literature, they experienced oppressive conflict within the collaborative team, despite differences in age, culture and seasoning. Personally, professionally and as advocates for vulnerable, voiceless clients, both women felt marginalized and misunderstood.

Many social workers are unprepared to address conflict tinged with social injustice among professional colleagues. Gendered and racialized disparities within faculty may account for some of these discrepancies. Women of color remain underrepresented in qualitative research, quantitative research and at all levels of the professoriate in American colleges and universities (Kelly & McCann, 2014). The U.S. Department of Education (2012) reports that female faculty of color make up 10% of associate professors, 7% of assistant professors and 3% of full-time professors. With limited numbers of women of color as faculty in a field of predominantly women, how do social workers acquire, model and replicate the skills to manage and address conflict, social injustice and inequality?

Indeed, addressing inequality within a profession designed to address inequality is a complex endeavor. The multiple marginality of gender and racial inequities within the field may contribute to the inherent challenges in discourse about intersectionality. Social work is one of the select fields dominated by women. In 2010, 87% of Master's level graduates from social work programs were women (Council on Social Work Education, 2010). Despite this prominent stratification of gender, women are still not represented in leadership roles. A national survey of nonprofit agencies found that while 75% of the workforce was comprised of women, they held only 21% of leadership roles (Lennon, Spotts & Mitchell, 2010). The demographics for race are even more troubling. The previously mentioned investigation into the demographics of social work education (2010) found that 52% of new graduates were white, followed by 13.6% African-American, 8.8% Latino and 3% Asian. This disparity widens throughout careers; 84% of leadership positions at non-profit agencies are held by whites (Halpern, 2006). Arguably, the decisions that shape the future of the helping professions and the needs of disenfranchised, vulnerable clients do not include the voices of women of color.

Though discouraging, statistics only tell part of the story. Those who are called to a service profession are driven by the desire to help the marginalized and make the world a better place. However, good intentions do not serve as a vaccine against systemic inequality. Conflict experienced as a woman of color requires navigating a nebulous cloud of uncertainty: is it a simple miscommunication or an indication of something more sinister? In a professional workspace comprised of a transdisciplinary mélange of disciplines and intersectional identities, one often cannot know. This uncertainty could greatly diminish the confidence of women of color when the impact of their voices will provide a much needed balance to the field.

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Care by a Caregiver: The Use of Self in Qualitative Research

Jennifer Christine Hughes

Abstract: This narrative, reflective paper discusses a qualitative research study on multiple sclerosis (MS) caregiving in which the author/researcher utilized her own caregiving experiences and shared with the study participants in open dialogues. It examines the choice to research a topic with a close personal connection, i.e., the use of self in research. Moreover, this paper discusses the use of reflective journaling to gain greater awareness during the research process, and to assist with data analysis. Intimate passages from the journal are shared throughout the narrative concerning shared experiences, self-care, and topic analysis. Discussions are framed chronologically as before, during, and after the qualitative study was completed. The experience of caring for a partner with MS is central to this reflection, and the paper provides insight into that experience along with a discussion of the practice of using oneself in research.

Keywords: use of self in research, multiple sclerosis, caregiving, reflective journaling

Introduction

My involvement with qualitative research has been a remarkable journey both professionally and personally. As part of my dissertation research, I chose a topic with which I have a close personal connection. I am a female multiple sclerosis (MS) care partner, and my husband has had the diagnosis of MS for more than 20 years. During that time, I have provided varying levels of care for him. MS is a disease that primarily affects women, and women traditionally provide the majority of unpaid family care; thus, the MS caregiving experience is a unique situation for exploring gender roles in caregiving (Nodder et al., 2000). This illness has caused great personal loss to my husband, John, our four children and me. MS, however, also provided me with an opportunity to return to academia, complete a PhD in social work and conduct research involving MS caregivers.

I am certainly not the only qualitative researcher who has chosen a research topic that hits close to home; many others have done the same. In this paper, I will explore the use of self in research and reflect on my dual role as both researcher and caregiver. Further, I will explore my choice to research a topic with such close personal connections. My situation allowed me shared access to the MS caregiver experience during the research process. My original intent was to use my experience and knowledge about MS and caregiving as an advantage in connecting with the participants in my research. In the end, my research and its results became a source of personal growth and inspiration to me. In my research, I was able to transcend the role of researcher and fact-finder by sharing the lived experience with my participants, thereby deepening my perceptions of care as I identified with caregivers and care receivers alike. During this journey, I developed a substantially deeper understanding of my research topic and myself simultaneously.

Understanding Multiple Sclerosis and Family Caregiving

MS is a progressive, degenerative neurological condition that is unpredictable and results in a wide array of symptoms and disabilities. It affects more than 2.3 million people worldwide. MS is an immune-mediated disease in which the body's immune system attacks the protective lining (myelin sheath) of the central nervous system, thereby forming "sclerosis," or scar tissue. This impairment results in damaged or destroyed nerve impulses (National Multiple Sclerosis Society [NMSS], 2016a). The course of the disease places a burden not only on those with MS, but on their caregivers as well. The severity and symptoms of MS vary greatly from patient to patient and include fatigue, numbness, walking difficulties, balance and coordination problems, bladder and vision problems, dizziness, vertigo, sexual dysfunction, pain, impaired cognitive function, emotional changes, depression and spasticity (NMSS, 2014). With recent advances in medication management, individuals with MS are having fewer and less severe exacerbations of symptoms than in the past. Further, medications delay the onset of significant disability, thus allowing MS patients to continue living in their own homes longer and require less institutional care (NMSS, 2010). These advancements are good news for the patient; however, they place additional responsibilities on care providers.

Care for MS patients may be informal and unpaid or professional and compensated. 80% of informal home care is provided by live-in relatives, primarily the patient's partner (Carton, Loos, Pacolet, Versieck, & Vlietinck, 2000). In other words, the bulk of the responsibility of in-home care falls to the patient's loved ones. Patients without such a relative to provide in-home care must utilize other forms of support on the MS care continuum, such as friends and family who do not live in their home, personal care services, homemaker and chore services, skilled nursing, or rehabilitation services (NMSS, 2016b). Individuals who require professional care assistance must rely on private income, health insurance, or government-funded insurance programs for payment of these medical-related services. In-home care remains much more cost-effective and desirable for both cost and other reasons than out-of-home care.

In general, MS is a costly disease, especially with the recent addition of self-injectable drugs. The cost of care increased by more than 35% per patient over a 10-year period, from $9,515 per patient in 1995 to $12,879 per patient in 2004 (Kunze, Gunderson, Gleason, Heaton, & Johnson, 2007). Disease-modifying therapies in the United States can cost upwards of $48,000 annually, per MS patient (Goodman, 2012). These costs have contributed to the ongoing conversation about health care cost concerns in the United States. Some other nations have had a form of nationalized health care for some time now; therefore, their costs are lower than in the U.S. (Russo et al., 2004). The National Multiple Sclerosis Society (NMSS) supports continued overhaul of the U.S. health care system and provision of health care cost assistance to individuals with MS. The NMSS estimated the cost of MS to be around $70,000 annually per patient (NMSS, 2016c). It is financially devastating to many families not only because of the direct costs of the illness but also because of the indirect costs, namely loss of potential earnings for both the patient and the caregiver.

Aside from the financial burdens, the lack of predictability in onset of symptoms make MS an extra challenging disease for patients and loved ones alike. Because the disease's process and symptoms vary significantly from one individual to another, it is difficult to predict the individual's course of MS. Although rare, some individuals with severe disability may experience infections and die prematurely. The NMSS reported that the overall life expectancy for a patient with MS is 95% of normal life expectancy (NMSS, 2014). However, the effects of MS are more insidious than this rate implies. For example, MS generally impairs the individual's ability to complete many of the activities of daily living.

Family care partnerships are vital for patients with chronic illnesses and for keeping patients with MS in their own home as long as achievable. Prior research has been conducted on caregiver stress (Pearlin, Mullan, Semple, & Skaff, 1990; Robertson, Zarit, Duncan, Rovine, & Femia, 2007; McKeown, Porter-Armstrong, & Baxter, 2003), caregiver assistance (Dobrof, Ebenstein, Dodd, & Epstein, 2006), and caregiver burden and stress (Phillips, Gallagher, Hunt, Der, & Carroll, 2009). This past research has shown that providing care for a chronically ill individual is generally viewed as a stressful situation for caregivers and has a profound impact on not only the patient's social roles, but his or her family's well-being (Robertson et al., 2007). These caregivers are at risk of increased stress and depression as well as poorer quality of life (Khan, Pallant, & Brand, 2007). Providing care for someone, especially over a long period, can be overwhelming, and caregivers who encounter competing demands (e.g., work/career demands on top of full-time caregiving) are especially prone to depression (Wang, Shyu, Chen, & Yang, 2011).

Schwartz and Frohner (2005) and Pakenham (2005) addressed the importance of informal care specific to MS caregivers and agreed that providing assistance to the family caregiver benefits both the patient and the caregiver. Caregivers find themselves in a position for which they are ill-prepared, but their willingness to take on this role offers multiple advantages to the patient. Unlike individuals with the disease, however, caregivers do not view themselves as a focus for treatment, yet they, too, could benefit from assistance and support. Caregivers of patients with any disease (not only MS) face a difficult task and typically have a range of emotions associated with the care they provide. Additionally, providing a support system for the caregiver ultimately benefits both the patients and society because patients prefer the assistance of their loved ones, and such in-home care is also at a lower cost and reduces the expense to society (Dobrof et al., 2006).

Family caregivers do not always utilize available social support when they need it. O'Hara, De Souza, and Ide (2004) concluded that although MS patients receive considerable amounts of care from family members, those caregivers are not receiving social support from professionals in return. Moreover, these caregivers report clinically significant levels of psychological stress related to the care of a partner with MS (Pakenham, 2001). Providing greater support to caregivers is likely to reduce their feelings of burden, stress, and isolation. Such support will allow the caregiver to continue with his or her caregiving responsibilities, thus reducing the potential for the patient to require more costly, professional care assistance.

The availability of community resources and social support vary by location. Various online support networks are also available for individuals with MS, their loved ones, and their caregivers. Current services are typically accessed via the patient's treating physician, who provides information and referral services. Organizations such as the NMSS also have information and linkage services (NMSS, n.d.). The NMSS reports that 432,526 individuals with MS had registered with it as of the organization's last census in April 2014 (M. Nadvornik, personal communication, April 7, 2016). Exact numbers of individuals with MS are only estimated because individuals are not required to report their illness, but the NMSS estimates that 2.3 million individuals worldwide are living with MS (NMSS 2016d).

Understanding how many care partners of MS patients identify themselves as needing services or utilizing outside assistance is difficult. Currently, NMSS does not keep census numbers on care partners. It provides services to caregivers, including financial planning, referrals to health care professionals and community agencies, financial assistance, emotional support, education programs, self-help groups, and an online discussion forum for care partners (MSConnection.org). Other organizations, like Can Do Multiple Sclerosis (n.d.), offer lifestyle empowerment programs for people with MS and their care partners (Kalb, personal communication, April 7, 2016).

Although these services for MS caregivers exist, it remains difficult for caregivers to see themselves as an identified focus of treatment and support, and to therefore seek out needed assistance. Services to caregivers are provided more as an afterthought and not as a primary focus during treatment. These caregivers struggle with the demanding role of providing care to another and often go underserved and under-supported in the process. (Family Caregiving Alliance, n.d.).

My MS Story

My husband, John, a board certified internal medicine physician and a licensed pharmacist, has this life-changing disease. John received his MS diagnosis in November of 1993, just after our engagement. We married the following March. MS episodes occurred several times during the early years of our marriage. Those episodes were unplanned and random, and they changed our life plans.

We took the minor exacerbations of the illness in stride. For example, on one occasion we had to leave a function early, and on several occasions, John had to wear an eye patch for intense vertigo. It was an annoyance that we handled. However, our lives changed drastically during our fourth pregnancy. John suffered his most significant exacerbation, which resulted in extensive vision impairment in his left eye. During previous episodes, John had experienced vision problems that had left him with central vision loss in his right eye. Now, John was totally blind in his left eye. The lack of vision in both eyes required him to leave his job as an emergency room physician. I was seven months pregnant at the time and worried how I would drive myself to the hospital when our fourth child arrived.

John was unable to complete tasks required of a primary care physician, like suturing or looking in a patient's throat or ears. He spent three years not working and received disability insurance. It was during that time that I was able to attend the University of Utah to pursue my Ph.D. studies in social work. The opportunity to return to school was a direct result of my husband not working, as it allowed my family to both relocate and remain economically stable. My husband provided care for our children and support to me; without his care, I would have remained a master's degree-level social work clinician.

Although I believed our situation with MS was less severe than that of others, I still felt a unique connection with spouses and caregivers of individuals with MS. I understood, personally, the random attacks that strike when no one is watching. Like many others, I lived the experience of compartmentalizing MS, tucking the disease away in a box while I tried to move on with living life and take care of my family. That strategy always worked for a time, until the disease ripped the box open and showed its ugly self again in some bold manner. I had firsthand understanding of how MS attacked the flow of a family, forcing members to stop and respect the power of the disease. In many ways, it was not just John who lived with MS, but all of us in his immediate family. And we each knew that, at any moment, the courses of our lives could change, and we would be forced to proceed in a new direction at the disease's command. The rhythm of our lives went something like this: recover, move on, forget and repeat. I felt defenseless against the disease, and I hated the loss of control inherent in MS.

At one point, someone close to me suggested that I must be happy that my husband lost his eyesight because it allowed me the opportunity to work toward my PhD. I told that person that I would never be happy that my husband lost his eyesight, but that I could truly understand that sometimes people find the strength to make something good come out of something bad. My life was a swirl of intense, personal emotions as I began thinking about possible research topics for my dissertation. For obvious reasons, I was drawn to the topic of MS, and focusing my research on unpaid-nonprofessional caregivers seemed fitting–these were people with whom I had a shared experience.

It is important to note that while no MS experience is typical–every case differs from one another–my husband's experience has not been nearly as devastating as others'. John has a strain of MS that has not been as progressive or as debilitating as many patients experience. His disease attacked his vision significantly, but he remains able to walk, move, and meet the demands of daily living with minimal assistance. Those with a more aggressive form of MS are less fortunate in terms of the impact on their daily lives. Of course, some experience fewer symptoms than my husband.

Before the Research

When my husband had to abruptly stop working due to the extreme exacerbation of his illness (causing the vision loss in not only one but now both eyes). He found himself at home, spending large amounts of time in isolation, and miserable. In focusing my dissertation research on MS, I hoped my husband might become interested in my research and write about his personal experience with the disease. I thought this opportunity might engage his brain and draw him out of his sense of isolation.

I began looking at peer-reviewed journals on MS. The articles that most fascinated me were the ones on caregiving. I became drawn to studies that focused on the family caregiving experience, but I noticed a gap in the existing research. Although research on general care and caring for patients with other illnesses was available, research focused on MS caregivers' experiences was generally lacking. Therefore, my questions for this research arose directly from my personal experience and my review of the literature.

I designed a qualitative study that looked at perceptions of MS care from both the caregiver's and the care receiver's viewpoint, to see if traditional gender roles affected the care experience, especially given that MS affects women more frequently than men. I interviewed 20 participants individually first; then I interviewed each care receiver/giver dyad in a follow-up, joint interview in which I examined perceptions of the care experience. I looked at the caregiving experience, care roles and responsibilities, and the role of social support among the dyads (Hughes, 2016). Prior to beginning my research, I thought carefully about sharing my own situation with the participants and, in the end, determined I would be transparent and identify as a caregiver.

To Share or Not to Share

I struggled with whether to share my personal experience with my research study participants, but after much thought and deliberation, along with a review of relevant research, I decided that doing so was the best decision. I am a fairly transparent person in general, and I believe a small amount of self-disclosure can be useful. As a clinical social worker, I had developed over time the skill of minimal self-disclosure. But still I needed to determine any prior precedence and insights regarding choosing a research subject with a close personal connection, so I turned to other researchers.

Padgett (2008) discussed studying the familiar versus the unfamiliar, and identified two advantages of sticking with a familiar topic for a qualitative research study. The first advantage is easier and faster development of rapport with the participants. The second is the jump-start in knowledge acquisition. Padgett also noted that a disadvantage of researching a familiar subject is the risk of being too close to the subject matter. Knowing too much about a subject matter can create blinders and lead to premature assumptions and conclusions.

I found several examples of excellent qualitative studies that were conducted by researchers with a close personal connection to their subject that supported my desire to research MS caregivers. These included research on disability conducted by Zola (1983); on divorce, by Riessman (1990); and on working parents, by Hochschild and Machung (1989). Perhaps the best example of such a study is that of anthropologist Robert Murphy, who suffered from a neurological condition that gradually restricted his movement and resulted in his death. He made tremendous contributions to disability studies with his book The Body Silent (1990). Toward the end of his life, he "used his own intimate experience of disability and his intellectual acumen as an anthropologist to broaden our understanding of human behavior" (Goldin & Scheer, 1995, p. 1443).

I believed participants in my study would be more severely ill than my husband, so I felt there was less potential to assume that we would share a mutual understanding of the care experience. I also believed the use of my close connection to MS and caregiving would facilitate transparency. My status as a caregiver and an insider to the disease, I believed, would allow participants to feel a connection with me as the researcher and therefore more comfortable sharing their experiences. This shared experience of similar burdens, I thought, would strengthen the research.

To be clear, there are also limitations to a study in which the researcher discloses personal information with participants. In this study, the most probable challenge posed by personal sharing was that participants may have assumed a shared understanding and thus not offered as complete an explanation to the phenomena being studied. During the participant interviews, I was willing to answer questions about my experience with MS. However, I used my clinical skills to bring the discussion back to participants' own experiences. My goal in using personal disclosure was to make the participant feel comfortable in the interview. I was a caregiver and an interviewer focusing on a participant's experience. I set limits to what I shared with the participants and professional boundaries within the interview if the participant became overly concerned with my experience. For example, I told one participant, "I am interested in hearing about your experience with caregiving. I can answer questions about my situation but I really want to hear about yours." One way I kept the interview focused on a participant was to probe more deeply in order to elicit rich explanations. My background as a clinical social worker undoubtedly assisted me in conducting research interviews. While developing empathy and understanding of a participant's experience, I was able to use my clinical skills to encourage a deep exploration of that experience. For example, I explored comments made by a female patient, who I will call Carol for the purposes of this paper. The question began with my inquiring about support groups:

> **Jennifer (Researcher)**: Have you ever participated in a support group?
> **Carol (Participant)**: No. I'm afraid.
> **Jennifer**: What are you afraid of?
> **Carol**: It seems like the more you know about it, the more it eats away at your life. You know? I'm ignoring it. I'm ignoring it.
> **Jennifer**: So keeping some distance from it . . .
> **Carol**: Yeah.
> **Jennifer**: Is that what's keeping you safe?
> **Carol**: I hear from people that I haven't talked to in eons that'll call me and say, "I just had an aunt or a sister or a friend or somebody who was diagnosed with MS, blah blah blah." Why are you calling me?
> **Jennifer**: How does that make you feel?
> **Carol**: Well, I guess it makes me feel I'm glad that I can be there for them, to have someone to call.
> **Jennifer**: Mm-hmm.
> **Carol**: But I can't tell them anything any different than, you know, a doctor or anybody else will tell them.

This excerpt is rich with emotion, authenticity, and expression that goes beyond the initial question.

I was also able to ask questions for clarification. For example, in the following exchange, the caregiver, Ralph, was asked if he was dependent on or independent of his wife. Ralph responded that he was dependent. I wanted to know more than that, so I followed up with a question for deeper expression by the participant:

> **Jennifer**: Do you think that you're dependent on or independent of one another?
> **Ralph**: I'd say dependent.
> **Jennifer**: And tell me how you're dependent on each other.
> **Ralph**: Well, you know, I love her to death and I need her. You know, I want her. You know, I miss her when she's, you know, at work or gone during the day and I'm just sitting there with the cats, you know.

Exploring deeper and providing opportunity for clarification is one benefit of the use of self in research. The researcher can say, "I understand your situation; now tell me more, because I know there is more to tell." For example an exchange with a female caregiver named Sarah:

> **Sarah**: He has weakness in his hands. He's not real good at opening hard stuff anymore or lifting, you know, just the grasp. It just depends on the day though. That's not always but we never know if it's the MS causing the problem.
> **Jennifer**: Okay.
> **Sarah**: Just, if he's having a bad day or a good day. And he limps just a little, but nobody else would notice that. And he has a lot of cramps like during the night.
> **Jennifer**: In my experience, whatever happens to my husband, I instantly think it's the MS. But physical symptoms happens to other people too.
> **Sarah**: Right! But you immediately think MS and it might not be. I mean, the cramps, I'm like, 'Maybe you should just take calcium.' You know, because you read that.
> **Jennifer**: Right.
> **Sarah**: Or maybe you're dehydrated. Which, the cramps could be from the MS, or they could not be. I mean, I get them sometimes too.

Use of Self in Research

I made a decision early in my dissertation process to explore a situation that was personally meaningful and significant. I believe this, in turn, made for a richer research experience. The participants' stories were especially heart-wrenching for me because I shared a similar experience with the caregivers. I believe the participants divulged more of their experience knowing that we had this commonality. In addition, because of my experience, I was able to use language the participants understood. Consequently, participants may have felt safer and a greater sense of connection with me as the researcher.

One specific way I was able to relate to the participants was through our common knowledge of the available medications and the systems for delivering them. My husband has taken four different types of MS medication, so I am familiar with all of them as well as their side effects. For example, he suffered difficult side effects from interferon beta-1a medications. He experienced flu-like symptoms after each injection that lasted until it was time for the next injection. I also immediately recognized when a patient talked about taking Tysabri® (natalizumab), which my husband also takes. I knew that Tysabri®, a monoclonal antibody, requires an IV infusion every 28 days and must be administered at a medical facility (MS Lifelines, 2012).

Participants were interested in which medicine my husband took and how it was working. Some participants asked if my husband had a particular symptom that they experienced. In these instances, I carefully reminded myself to not assume understanding and instead allowed the participants to direct the conversation and share their experience. When asked, I answered questions and used my experience as a way to establish a connection with the participants. If asked, I was able to share some knowledge of the illness and my personal experience. During the individual interviews, 9 of the 20 individual participants asked me questions or discussed my experience and knowledge of MS. For example, here is an excerpt from an exchange with one male patient:

> **George**: My wife said your husband has MS too?
> **Jennifer**: He does, yes.

> **George**: How long has he had it?
> **Jennifer**: He has had it [for] 18 years.
> **George**: 18?
> **Jennifer**: Yes. How long have you had it?
> **George**: I've had it–well, I think I [have] had it longer. I was diagnosed in 2005, so I've had it for 6 years that I've been diagnosed with. But I knew something was happening back in 2002. My legs, my feet were getting heavy. Like when you step in mud and it sucks up your feet and you've got to pull them out, you know? So I knew something was up, but I was just–it was like 2003, I'm sorry–and my work was just downsizing so my job got eliminated. And I wanted to get back into education. And I knew something was wrong–I don't want to say [I] knew, I just felt something was wrong. Something was different. I didn't know if it was a nerve in my back or something. I had this really outrageous insurance that we had to pay on our own. So I thought, "Well I'm not going to mess with that." And then when I got my school job about a year later, I knew something was up.

Another female patient said, "But you know all about this because your husband has MS." The participants who did inquire did so about practicalities such as my husband's medication regime or the use of assistance in our home. Family caregiving can be an isolating experience; I believe some saw this as an opportunity to share and connect. I allowed the participants the opportunity to inquire and direct the conversation if they so desired.

During the Research

In order for me to adequately process this experience, my dissertation committee suggested I keep a self-reflective journal. Self-reflective journals provide an opportunity to bring mindfulness to a situation, develop insights and explore repeating themes. Researcher Ortlipp (2008) discussed their use and advocated using of such exploratory processes in qualitative research. I personally found the journal to be a way to investigate my intense emotions after completing an interview. I even viewed it as another piece of the information I was gathering for my research.

I thematically coded my journal entries, and the content that I most frequently coded had an emotion of sadness. Conducting the interviews was far more emotionally intense than I anticipated. Writing in the journal gave me an outlet to process these emotions and provided an important sense of closure to each interview.

My self-reflection began after my first set of interviews with a male caregiver and a female patient. I interviewed the female patient first while the caregiver waited. At one point during the interview, we had to stop so the caregiver could lift his wife from the wheelchair and carry her to the restroom. She appeared so frail and damaged. During his interview he rationalized:

> Her symptoms are not that bad. I feel that we're not as bad off as the other people that you're interviewing maybe. Some of them have more serious issues than what we have. Just from what I've read, from what I've heard and so forth.

I was shocked because he seemed completely unaware of how seriously ill his wife appeared. I couldn't wait to journal about my feelings. That journal entry read:

> That person's disease is so severe she needs assistance transferring from her wheelchair to the restroom and yet she is still telling me her MS isn't as bad as others who have it worse. Really, her disease is pretty bad. I do that myself. I rationalize this experience by telling myself that my husband's illness isn't as bad as some. I feel sad for the woman who can't use the bathroom on her own and sad for myself because someday that might be me, transferring my husband from wheelchair to toilet.

Later, I referred back to and reflected on my own journal notes in conjunction with my analysis of the interview transcripts. I was able to use my journal as an opportunity to identify themes in the interviews and to make a connection between MS caregiving and the process of grieving and loss. Grieving was not one of my original theoretical frameworks. This theme only emerged through the journaling process. In reading my entries, I noticed I recorded emotions that are embedded in Kübler-Ross's stages of grief (Kübler-Ross, 1969). Kübler-Ross's theoretical explanation describes grief as manifesting itself in stages that include denial, anger, bargaining, depression and acceptance. Noticing the use of the word "denial" over and over again in my journal illuminated a connection between grief and caregiving that I had not previously considered. Upon realizing this connection, I wrote about it, noting that the participant spoke of anger, denial and acceptance. This discovery raised new questions and observations for me. I wrote:

> Is the process of providing care interwoven with the process of the loss associated with death and dying? Are caregivers grieving? I need to keep track of this and see if other participants discuss these emotions. I guess it's not that much of a leap to think of caregivers as grieving. They are probably grieving what used to be. Providing care is a type of loss. The patient has lost the ability to do something and the caregiver has lost what used to be.

Connecting this theme of grief with the interviews, I noted that denial was discussed as a coping skill by 4 of the 5 male patients in my study. For example, Kyle said, "I was in denial for like the first 6 months," and another man named Mike said that denial is like a self-defense mechanism.

Incidentally, Kübler-Ross (1969) discussed the concept of denial as a temporary defense that is later replaced by some feelings of acceptance.

Journaling helped me maintain focus on the participants' experiences and not get lost in my own reactions because I knew that after every interview, I would take an opportunity to write about my own thoughts. Reflective journaling gave me a concrete forum for expressing and processing my emotions, which in turn helped me maintain an emphasis on participants' experiences during interviews. The purpose of my research was not to process my own experience, and the structured outlet of a journal helped me keep this focus.

My prior clinical experience brought an additional layer of richness and depth to the situation. I used the journaling process not only as a personal outlet but as a prompt for developing additional questions to ask participants during follow-up interviews. After one set of interviews I wrote:

> This patient minimizes the significance of her illness. I am interacting with a woman with severe illness, and she is telling me how her illness isn't really that bad. She is almost in denial of the seriousness of her health problems. Is this a coping technique? Could this be denial? On the other hand, her husband has an acute understanding of the significance of his wife's condition. There appears to be a disconnection between the caregiver and care receiver in this particular couple. Is the couple aware of this difference? I will explore further in the joint interview.

At times I felt drained. I was emotionally exhausted after some interviews in particular and had to force myself to journal. I had a long car ride home, and I was grateful for the time to shut off my brain during that drive home. One time, I remember sitting in the parking lot forcing myself to my notepad. During that session I wrote:

> I feel immensely sad. This is a horrible disease. I feel badly for the patients and the caregivers. Everyone is just waiting for the next shoe to fall, and meanwhile they are all playing the same game that some other guy has it worse, so that makes them somehow lucky. No wonder MS patients isolate themselves. I feel so bad for these patients and their caregivers.

By the time I was several interviews into the research, I had moved to a place of personal fear. The interviews were hitting close to home. I wrote:

> What if John's illness gets worse? What if he's in a wheelchair like this participant? How will I manage my kids, my work and caregiving? I am so afraid this will be me in the future. I could be burdened with these same responsibilities, and how will I ever find the strength to do it all alone? This is not what I bargained for.

After the Research

When I began this research, I thought my husband's illness was well contained. I, like so many of the participants I interviewed, believed others "had it worse," that we were one of the "lucky ones." I felt we coped with our situation quite well. I now know that caregivers and patients learn to adapt to the challenges using a variety of available resources. I learned that many people with MS and caregivers describe themselves this way. It is an adaptive coping strategy used by many. Even those who are greatly affected by the disease describe themselves as one of the lucky ones. I used exactly the same coping skill I observed in many of my study participants. When I coded the interview transcripts, I categorized this observation under the theme "Some other guy has it worse." I discussed this theme as either part of the grief stage of bargaining or as a sort of "magical thinking." Bargaining is seen by Kübler-Ross as an attempt to postpone the worsening of the situation by living right (Kübler-Ross, 1969). This is a form of magical thinking or casual reasoning, in which a person looks for a connection between potentially random events (Zusne & Jones, 1989). In my journal I wrote of my own thoughts and experience with this type of thinking:

> This feels like this participant is coping with the experience by using magical thinking, like they can somehow ward off the disease by living a good life and being a good person. As if some higher power has the ability to keep them healthy because they had good behavior. Is this superstitious, magical thinking or merely a strong faith perspective? I am reminded about the time people from our church told me to pray for John's vision to return. John as a medical provider told me he was pretty sure the damage to his eyes was so extensive he would not get his vision back, but there we were on Sunday and a do-gooder was trying to instruct me on the power of prayer. It didn't work. John didn't get his sight back, so does that mean I totally suck at prayer? Or are we not good enough? I see this as a coping technique that many participants are using, but I worry about the danger in magical thinking or bargaining. What if it doesn't work? MS is a progressive degenerative illness, so patients get worse. It is the very nature of the disease.

Over the course of my research, my husband's symptoms worsened. The interview conversations hit me hard when they involved discussion about experiences similar to mine. My research forced me to process my own emotions surrounding the illness, and led to a range of emotions, from overwhelming sadness to inspiration. For example, I became acutely aware that MS is an isolating disease. During an interview, a female patient stated:

> I used to go places and see my friends...but I can't drive or anything anymore, so I don't see much of them anymore. They're working, and they [have] family and stuff too. We just don't do things anymore.

In response, I wrote in my journal:

> MS is such an isolating disease. This couple stopped socializing. They are probably unaware that they have isolated themselves, which is the very same thing we did when things got worse. We stopped hanging out with friends and going places. It wasn't the friends that pulled away from us, it was us pulling away from socialization.

Many people with whom I spoke did not know others with MS or have the opportunity to speak with another patient or caregiver. I was in that same situation. With MS, the mere act of living with the illness forces people to isolate. As the participants spoke of isolation, I realized that we, too, had isolated ourselves as a way to cope and survive. I reflected on our situation and realized the drastic changes that occurred in our life following several of John's MS attacks. Making this connection between the participants' description of inaccessibility and loneliness, and my personal experience with isolation, provided me another area for exploration and for future research.

When I started my research project, I was looking for a topic that was of interest to me, but honestly I wanted to get the work done so I could graduate. I told myself that the best dissertation was a finished dissertation. I was not striving for perfection, just completion. Somewhere along the line, I realized that I had gathered important information both about the MS care experience and the use of self in research. I felt a huge sense of accomplishment and pride. My family traveled to Utah with me for classes, and they came with me to my graduation ceremony. I felt as if the entire family earned the degree because of the sacrifices everyone made. Our children saw their dad cooking dinner, doing laundry, and handling other housework while Mom learned statistics. My Ph.D. was our collective accomplishment. The illness drew us together in our shared burden, but is also drew us together in pride of this achievement.

I am not unlike the care partners I interviewed for my research. Like them, I did not identify myself as a target for treatment. After all, I did not have the disease–my husband did. I'm healthy, I thought; I don't need treatment. And so I sat on the sidelines, listening to my husband's physician tell us about medications and treatments, never once thinking that I should seek assistance. In one journal entry closer to the end of my data gathering process, I wrote:

> I continue to question why these caregivers are not seeking any type of formal assistance, but today it hit me like a giant "ah-ha" moment. I have never sought formal assistance either. Am I not just like them? Wouldn't I benefit from some type of programming? I rationalize that I am a high-functioning individual and I can do this without assistance, but isn't that what all the caregivers are thinking too? What makes me resistant to services? Probably some of the same things that make the participants resistant to services. I also believe because I am in a helping profession I am not sure how good I would be at receiving treatment. It's hard for me to turn that off and . . . find myself in the place of healer rather than taker. It would be like more work after work and the thought just overwhelms me.

Care partners have an enormous burden, but in our current system of care, we do not identify caregivers as a focus of treatment or concern. If caregivers do manage to seek out services, it is as an afterthought to the service demanded by the person with the illness.

We are providing a disservice to family care providers by not making them a focus of support and treatment. We also should examine the complex reasons behind why caregivers may not seek out such services. In my situation, despite my background in a health-related field (social work), I didn't see myself as a patient. Like other clinicians, I had a misled belief that mental health providers should have a "high level of psychological wellness," (Norman & Rosvall, 1994, p. 450) and that seeking treatment would be an admission of inadequacy.

Use of Self-Disclosure in Research

Personal experience with MS may be both a strength and limitation of a qualitative study design. As I was careful to keep in mind that I was not the center of my research, my intent was to use myself and my experiences to add a richness and depth to my study. I believe that enhancement occurred. For example, self-reflection and journaling provided an opportunity to explore the use of myself freely. The strength of my experience allowed me to gain wider access to information in order to co-construct the reality of this particular social situation. Results of qualitative research are open to the researcher's personal biases; therefore, member checking was extremely important and a deliberate part of my research process. Fortunately, that step of checking for bias yielded minimal results besides strengthening the overall process.

This research forced me to face the reality of my personal situation. I attempted to use the technique of intellectualizing, whereby a person deals with emotions using facts and data (Arnold, 2014). Some participants wanted more than mere information. They wanted me to answer the same questions I was asking of them. One female caregiver asked: "How do you do this? How do you handle having a husband with MS plus being a mom of four kids?" At first I wanted to answer with knowledge about the disease, but I quickly realized her question wasn't about gaining facts; it was about the shared experience of both of us living as care partners to husbands with the same illness. Resisting the urge to rattle off data, I answered with authenticity, telling her, "Some days it's harder than others. Today was a good day. Last week, not so much. It's day by day. How do you handle these responsibilities?"

If I were to repeat this study, I would do it in the same manner–choosing to self-disclose. The use of self in this research brought about deeper conversations and emotions. My research and understanding were stronger because of using myself in the research process. For example, the decision to remain hidden and unknown in social work research has merit in many instances. However, the decision to share is beneficial to researcher and participants alike, and in my research in particular, this decision led to much greater insight and development of understanding about the caregiving experience. The use of self in this research on MS caregiving led to transparency, authenticity, genuineness and substance in the interviews.

My Story, Continued

John went back to work part-time in July 2008, three years after he stopped his clinical work and just after I took my competency exams. He is a preceptor at a residency clinic, where he supervises medical residents and provided treatment in a federally–qualified health care setting where his vision is not required. This university is a leader in providing necessary accommodations to assist people with disabilities with gaining employment.

This week John received his 100th dose of Tysabri. The clinic made him a sign and gave him a brownie. He holds the record for the longest time on this infusion medication at this clinic, which is something to celebrate. Today, he is well, which is also something to celebrate. So many others have it worse-really.

In the fall of 2014, I took a tenure-track position as an assistant professor of social work at the same university where John works. We now commute to work together. His MS remains stable. My daughter, an English major, just text-messaged me this week with questions about her father's MS. She is writing about MS caregiving for a literature assignment. I guess writing about it runs in the family. How could we not take an interest in this topic, whatever our professional context? MS is a disease that, even when well contained, dominates life; it's always lurking in the background with the potential to rear its head and interrupt life. Caregiving, too, is as draining and all consuming as the disease; just in different ways. For now, we are thankful for this period of stability.

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My Cisgender Comeuppance

Christopher Cotten

Abstract: The author, a cisgender (i.e., not transgender) white, gay male, describes his experience as a curriculum consultant on an HIV-prevention intervention for young transgender women. In spite of being well-read on the subject of the perils of nonaffiliated researchers doing sensitive research within oppressed populations, he unwittingly commits a gaffe that is illustrative of those very perils.

Keywords: cisgender, transgender, research, HIV/AIDS

In a 2001 Matthew Diffee cartoon in *The New Yorker*, two homicide detectives stand looking down at a corpse. “From the violent nature of the multiple stab wounds,” one says, “I’d say the victim was probably a consultant.” At the time I saw this cartoon, I was working as a clinical consultant for a number of child and adolescent mental health agencies in a large Midwestern city. Although I am not aware of having stirred up homicidal fantasies among those for whom I consulted, I do recall saying to friends, “You know what consulting is, right? It’s when people pay you lots of money and then *don’t* do what you recommend”–which is to say that the work was not always satisfying.

So I was intrigued when I received a call about a different kind of consulting assignment. The Director of Research at a large LGBT Health Center had been given my name by a professor of Psychology under whom I had trained as part of a fellowship in HIV Prevention Research. As part of the fellowship, I had collaborated on the creation and writing of manualized curricula for federally-funded HIV prevention studies with youth. The director had received a small feasibility grant from a federal agency to create and test an HIV-prevention intervention for young transgender women. Transgender women are considered a high-risk population for HIV infection: a 2008 meta-analysis by Herbst and colleagues from the Centers for Disease Control and Prevention (CDC) estimated an HIV prevalence rate of 27.7% (Herbst et al., 2008). A study focusing on young transgender women suggested similarly high infection rates (Garofalo, Osmer, Sullivan, Doll, & Harper, 2006).

During my interview, the director, who was the Principal Investigator (PI) on the grant, explained that the project’s original consultant, a white cisgender heterosexual women, had been let go because the two curriculum writers–a young white lesbian and a young white trans woman whom I will call Elizabeth–felt that they couldn’t work with her. Truth be told, he explained, “They don’t want another consultant; they think they can do it themselves.” In fact, he reported, I might encounter a little hostility because I am a white, cisgender male.

This sounded exactly like the kind of challenge I relish. Some of the work I had found most gratifying in the past had been with teams of unwelcoming, dispirited, and even antagonistic human service workers. I’ve never presented myself as an expert (though some of the people who hired me did); it’s the workers who are the experts. My goal has always been to help them come up with solutions to seemingly intractable problems.

When the two young women were brought into the office, I laid down my weapons: “I have no interest in taking over this project,” I told them. I’d written curriculum for two different federally-funded manualized HIV-prevention interventions for youth, but I assured them that it would be them “in the driver’s seat.” I’m sure that being gay gave me a little bit of credibility (at least I bested the previous consultant in that regard), but my experience with the transgender community was limited, and I couldn’t pretend it wasn’t. Something must have clicked, because I was hired immediately.

Shortly thereafter the young lesbian left the project to go to graduate school. An additional but similarly inexperienced curriculum writer, a young African-American transgender woman I will call April, was hired as her replacement. We quickly dove into the work, since we were on a strict timeline. Our charge was to create a six-session HIV-prevention intervention manual tailored to young transgender women. We decided straightaway to make the sessions experiential rather than didactic. I met regularly with the writers to brainstorm ideas, divide up the work (they did the majority of the writing), and schedule deadlines. We created games and role plays, used lots of humor and creativity, and incorporated media and audiovisual materials. I proofread the scripts and provided feedback, but what I mostly did was learn a lot about transgender culture and how to work with the population. I am ashamed to admit how little I had heretofore known about trans folks, their challenges and resiliencies. In the past I had even questioned the appropriateness of the "T" in LGBT. After all, the "L," the "G," and the "B" are about sexual orientation while the "T" is about gender identity: shouldn't these be two *different* movements? With "Ellen" and "Will and Grace" America had finally begun to accept gay people; acceptance for transgender people seemed eons away. Now I was working elbow-to-elbow with two members of the community, and the work was exhilarating.

Throughout the project I remained more than aware of my privileged status as a white male, as cisgender, and–in a relative sense–as gay. At one of our meetings I recall telling Elizabeth and April that I felt conflicted about being a consultant on a project focused on a community of which I was not a member. Both women told me that they considered me an ally–that I had essentially proven my mettle and good faith. For better or worse, we all realized that the research community–those who give and get the grants and those who publish academic journals–do not deem people credible unless they have advanced degrees and academic affiliations. But trans individuals are not always welcomed in educational settings, including postsecondary education: more than a third report abuse and harassment by students, instructors and staff (Grant, Mottet, Tanis, Harrison, Herman, & Keisling, 2011). In spite of their mistreatment, they persevere: trans people are nearly twice as likely as the general population to have earned a four-year college degree (Catalano and Shlasko, 2013)–a tribute to their determination. But until they gain access to academic posts and research funding streams, the grants will continue to go to members outside of their communities, and the publications will be written by the cisgender elite.

When we submitted the draft of the completed manual to the PI, the feedback was excellent, and the writers and I felt extremely proud of what we had crafted. The next phase of the project was piloting the curriculum; Elizabeth and April would act as the co-facilitators of the intervention. I had grown so close to them and so attached to the project that I decided to continue working with the team throughout the pilot and intervention phases, providing weekly clinical supervision to them as well as guidance and support regarding the running of groups.

The pilot was a success. The six 90-minute sessions, held at a drop-in center that catered to homeless and street youth, were spread over three weeks with two evening sessions per week. In spite of the fact that many of the participants were homeless or in unstable housing, retention was remarkable; the participants were really responding to the material. There was some minor tweaking of the curriculum based upon feedback from both the participants in a post-pilot focus group and from the facilitators, but we were able to make revisions in fairly short order. The intervention phase of the study began, and by the time the last cohort completed the intervention the proposed N of 50 had been attained.

By this time I had defended my doctoral dissertation and started my first job as a tenure-track assistant professor. The study's PI asked me to begin a manuscript that would focus on the process of developing the intervention's curriculum, which was unique and worthy of dissemination. I was of the mind that the manuscript should be written by the curriculum writers, who had, after all, written the bulk of the material and were members of the transgender community. But the PI felt that neither had the expertise to write a scholarly manuscript fit for a peer-reviewed journal: Elizabeth had her Bachelor's degree and April was currently pursuing one at a local university. The truth was that, although I had written plenty of long academic papers in my Ph.D. program, I too did not yet have a single publication under my belt. I could certainly collaborate with my colleagues, the PI told me, but I should be the first author.

When I approached the two women about joining forces to work on a manuscript (carefully leaving out what the PI had said about their inexperience), they were agreeable. But they also expressed frustration and resentment about what they felt was a general lack of confidence in them on the part of the PI (as it turned out, they were well aware of what I was trying to avoid sharing with them). The marginalization and lack of respect they felt was all too commonplace: this was familiar terrain for members of the transgender community. I tried to put a positive spin on the situation: we would make it a collaborative effort and we'd all end up as published authors in a scholarly journal.

However, I definitely felt conflicted about moving ahead. I avoided getting started on the process. I think Elizabeth and April were similarly ambivalent. The few half-hearted attempts I made to convene meetings went nowhere: all three of us had moved on to other projects, and whether it was logistics or avoidance or a combination of the two, we never managed to find a time to get together. Weeks stretched into months. Every now and again I would get an email from the PI saying "Where are we on the curriculum development manuscript?" and I would have to send a sheepish but upbeat reply: "Scheduling is a nightmare! But we're committed to the task. It'll happen!"

At the same time I was settling into my new role in academia, with its mandate to "publish or perish." The university where I was employed was not a Research One setting, but if I wanted to be successful and be awarded tenure and promotion, I needed to get some articles published. I felt stuck and uneasy. After yet another inquiring email from the PI, I locked myself in my house one weekend and wrote the paper. I listed myself as first author, with Elizabeth and April directly below me on the title page. I felt a mixture of accomplishment, relief, and even a little bit of pride. Eager to share my excitement, I immediately emailed a copy to Elizabeth and April.

A couple of days passed without a response, and I knew something was wrong. When I opened the reply from Elizabeth that appeared in my mailbox a few days later, my heart dropped. She was hurt and angry that I had unilaterally gone ahead and written a manuscript. To have included the names of her and my other "co-author" was doubly insulting. In fact, my entire effort was emblematic of how non-trans community members dominate and muzzle trans peoples' voices and agency. The manuscript was replete with bias and with assertions–such as the one extolling the virtues of community-based participatory research–she found scathingly ironic.

I felt devastated. How could I have been so stupid? I was entirely aware of the resentment and resistance that festered within the trans community after decades of "having [trans] identities and realities defined by nontrans researchers/gatekeepers" (Serano, 2008, p. 491). Elizabeth's feedback made total sense, so why hadn't it occurred to me beforehand? I had actually been under the impression that I was doing everyone a favor by pounding out a draft; now at least we had a document to fine-tune instead of having to parcel up the writing and start from scratch. I was overwhelmed with shame and self-recrimination. Writing about practice guidelines for those working with the trans community, Richards, Barker, Lenihan and Iantaffi (2014) stress that "it is important that writers and researchers, including graduate students undertaking dissertation projects, reflexively consider their agendas before embarking on their work," (p. 255). An ugly question hung over my head: had I put publishing and careerism ahead of deeply valued relationships? Just thinking about it made my stomach roil.

A second email arrived from April–the tone less overtly angry but just as affronted. I sent both women an email asking if we could meet to talk about what happened. They were both stinging from the incident and were not especially interested in discussing it, but with a little more persuasion they agreed to meet me at a local coffee shop.

The meeting was painful and tense. I apologized repeatedly, haltingly trying to explain how I had come to do what I had done. But my rationalizations sounded hollow and inadequate. The women had brought along a copy of the manuscript and began pointing out myriad offending passages. In addition to the factitious title page, even the very first sentence of the manuscript was a blunder (I had referred to transgender women as being "born anatomically male" instead of "assigned the male gender at birth").

Much of the rest of the paper seemed hypocritical: "Hill (2005) provides a number of caveats for non-trans researchers," I had written, "urging them to approach their studies 'with a sense of humility and recognition that trans people are experts on their lives' (p. 103)." In the same article I had referenced, Hill had cautioned cisgender researchers to "avoid '747 Research,' where they fly in, fly out, publish, and get tenure, never to return" (p.103). This sentence now struck me as blistering.

For me, the goal of the meeting had been to repair my relationships with Elizabeth and April. I told them that our friendship meant far more to me than a publication; for that reason, I would shelve the manuscript. I hoped that I could earn their trust back, but I left feeling dejected and hopeless. The next time I was at the research site I talked to the PI's research assistant (I was too mortified to speak to the PI directly) and told her what had transpired: I would no longer be working on a manuscript. My latest project–with the same PI–was assisting on an HIV-prevention intervention manual aimed at young men who have sex with men (YMSM). The work was pretty time-consuming and I more or less fell out of touch with Elizabeth and April.

A couple of years later I left my job at the university to work in Central America. Upon my return to the U.S., I relocated to the southeast and began a new faculty job. My partner on the YMSM project, a cisgender male community psychologist, contacted me to discuss collaborating on a curriculum development manuscript (*déjà vu*!) related to that project. As we embarked upon the literature review, we dug around for papers about developing ground-up HIV prevention interventions and found next to nothing. I even put my graduate assistant on the case–to no avail. When he lamented to the PI's research assistant about the dearth of curriculum development papers, she encouraged him to ask me about the manuscript I had shelved years before. To my surprise, I managed to actually locate the file and sent it to him.

After reading the manuscript, he urged me to re-open a dialogue with Elizabeth and April about revisiting and reworking the paper. His contention that it was imperative to disseminate scholarship about our unique curriculum development process echoed that of Cosgrove and McHugh (2000): "research that is not accessible, that is not distributed to the communities involved or that is not even published has little chance of affecting women's lives" (p. 832). The PI had been apparently asking about the abandoned manuscript as well, since the outcome of the trans intervention feasibility study had proven so successful that a new grant had been written and funded, and a two-city randomized control trial was currently underway.

I found Elizabeth's email address among my contacts and reached out. While acknowledging that our past experience with the manuscript had been painful, I shared that in our research for the YMSM paper, my colleague (whom both she and April knew) and I had realized that there is a gap in the literature about developing grassroots HIV prevention intervention curricula. Might it be possible to resuscitate the manuscript "in a fashion that would feel more collaborative and less insensitive?" (Cotten, personal communication, April 18, 2013):

> The development of [the intervention for young transgender women] was a major accomplishment, and one that deserves to be accessible to future scholars–especially since the intervention has continued. A paper could be an important contribution to a gap in the professional literature …Think about it. And then let me know.

More than two weeks passed. Then came a reply. To my surprise, Elizabeth had been under the impression–for years now–that the PI and I had moved forward with the manuscript and that it had already been published. She had counted it among a host of betrayals she and April–as well as other trans colleagues and clients–had endured at the hands of the LGBT Health Center where the study had originated. She avowed that–in spite of everything–the intervention manual represented one of the things in her life that she was proudest to have been a part of. Moreover, she agreed that a paper on the curriculum development really deserved to be represented in the literature. But she had spoken to April, who had said she was not interested in participating in a revision. And she had concerns that the manuscript would consequently be written by the two white members (she and I) of the team, leaving out the very important voice of the African-American team member. She ended, however, by saying she would be open to a conversation via Skype or phone.

A short time later I was contacted by April, who had apparently reconsidered and decided she was willing to join the dialogue after all. By then it was the end of a semester and I was neck-deep in grading and prepping for classes for the subsequent semester, so I told them I would be in touch. When I emailed a few weeks later, I didn't get a reply.

Two months passed and I found myself back in a familiar position: the PI was asking me about the status of the manuscript. I jotted out another email to Elizabeth and April, which I titled "Reaching Out" (Cotten, personal communication, August 7, 2013):

> "I wanted to check in and see where you stand regarding getting this … article revised and out for publication … I fear if we wait much longer it could be rejected by journals as being 'too old.'"

I would soon be leaving town to bring some of my students to Central America for two weeks, but I heard back affirmatively from both Elizabeth and April. Upon my return I sent an email proposing a conference call at the end of the week. I never got a reply.

What to do? Had I tried hard enough to forge a new and improved collaboration? Was I beating a dead horse? Had I said or done something to offend the two women again? If I moved ahead on the manuscript without Elizabeth and April was I once again flexing my cisgender privilege? Could I ethically defend pursuing publication based on the potential benefits that would accrue from the contribution to the professional literature?

Rescue came in the form of an email from an LBGT listserv I am a part of. It was an announcement for a one-day conference on LGBT research methodology. The organizers were requesting proposals for presentations, including the topic of ethical issues. I submitted a proposal based on my experience as a cisgender researcher on a transgender study. It was a case study/cautionary tale, but I also planned to pose the question regarding whether to move ahead on the manuscript. Perhaps members of the LGBT research community could give me some guidance concerning what my next step should be.

The presentation was accepted. I am normally not nervous about public speaking, but on the day of the conference I was full of anxiety. My biggest fear was that the audience would judge or condemn me. That didn't happen. On the contrary, the attendees–cisgender and transgender–were compassionate and empathic. One person told me to stop beating myself up. "I can't help it," I replied, "I'm a recovering Catholic: guilt and shame are in my DNA." The consensus was that I had done my due diligence and that I should move forward with revising the manuscript and submitting it for publication. The emotional relief, however mild, was immediate.

Though significantly reduced, my conflicting feelings about the article–yes, it has now been published, with the PI as my co-author–will probably never go away. In my doctoral program I had studied the perils of nonaffiliated group members conducting research with disenfranchised populations; heck, I'd even quoted some of the caveats in my manuscript. But it was not until I committed some real and consequential missteps–in vivo–that the dynamics of privilege and oppression in research really sunk in: my cisgender comeuppance.

Lessons Learned?

"Claiming the authority to speak for another person," write Richards, Barker, Lenihan, & Iantaffi (2014), "does violence to them in limiting their capacity to speak for themselves and to tell their own stories" (p. 252). Even queer academics, they caution, are not immune to exercising privilege when it comes to writing and research about trans people. Silencing my colleagues by stealing their voices was an individual act, but it was also illustrative of the kind of structural-level silencing "that [operates] in an invisible microcosm of power, privilege, and historical inequities" (Shpungin, Allen, Loomis, & DelloStritto, 2011, p.59).

Jacobs (2010) experienced similar challenges as a researcher for a community-based participatory action research project with low-income older adults in Rotterdam. "The existing power relations in society and institutional arrangements," she warns, "will inevitably infiltrate a project" (p. 370). She and her well-intentioned colleagues added a participatory action research approach to a research proposal–despite having no experience in the method–in hopes that it would stand out from the crowd of grant applicants and thereby get funded. They got their wish, and also an object lesson in the pitfalls "practitioners face implementing a bottom-up approach in a context which is primarily top-down and bureaucratically organized" (p. 370). Jacobs and her colleagues struggled with sharing power with their lay colleagues, especially given the pressure to meet funder deadlines and generate publishable data. Community participation waxed and waned throughout the project's phases, and resentment bubbled to the surface; the researchers, for their part, felt conflicted and guilty. How then, asks Jacobs, do community-based participatory researchers reconcile the competing goals of community participation/empowerment, academic quality, and the practical usefulness of the project?

> At the start of the project, before the community was involved, there seemed to be consensus about the project aims and the importance of community participation to realize them. However, in the course of the project it turned out that participation did not mean the same for everyone and also that different conceptions of participation could be present within one person. (Jacobs, 2010, p. 377).

"It is one thing to be aware of privilege and still quite another to proactively work toward minimizing its deleterious effects," write Travers et al. (2013, p. 417). Professional codes of ethics may offer guidance, though in this case, as Martin and Meezan (2003) point out, "of the numerous elaborations, explanations, and applications of ethical standards in social work and psychological research .... [n]one examine the application of ethical standards to research involving transgender populations" (p. 182). The National Association of Social Workers code of ethics standard 5.02(b) states that "Social workers should promote and facilitate evaluation and research to contribute to the development of knowledge." Helpful, though general. The more pertinent standard in my case would be in section 4.08(a), which states that social workers should "honestly acknowledge the work of and the contributions made by others," and take "responsibility and credit . . . only for work they have actually performed and to which they have contributed."

The moral of the story? Participatory research is a lot more difficult–and fraught–than meets the eye. Hazards abound. It is incumbent upon researchers to be vigilant about privilege, power differentials and competing pressures and loyalties (institutional and academic, in particular). Cultivating and maintaining a climate of continuous dialogue and introspection is crucial, though very tricky indeed, since all of this research does not take place in a vacuum. Rather, it is embedded in the multiple systems that conspire to undermine and silence those whose voices most need to be heard.

I have not engaged in community-based participatory research since "my cisgender comeuppance," which is a shame, I suppose. I attribute this to the fact that I relocated from a populous metropolis with a vibrant LGBT community to a small municipality without a critical mass of LGBT subjects. But perhaps I'm fooling myself–rationalizing my cowed avoidance of the complexities and exertion of such a methodology. What might happen if researchers begin to avoid this approach because of the difficulty of executing it satisfactorily? We will all lose.

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Reflections of a Pracademic: A Journey from Social Work Practitioner to Academic

Larry W. Owens

Abstract: This article provides a reflection on the author's transition from an experienced social work practitioner to a full-time academic, i.e. a pracademic. The article provides observations and insights on the unique challenges faced by pracademics in the academic setting. The author provides this narrative to assist pracademics wishing to enter the academy. Also, the article can encourage academic settings to give greater consideration of pracademics for their faculty.

Keywords: pracademic, transition to teaching

This article is a reflection on my transition from full-time social work practitioner to full-time social work faculty member. Some would say this change is not a transition because social practice includes social work education; that is, social work education is an arena of practice (Fox, 2013; Grise-Owens, Owens, Escobar-Ratliff, & Drury, 2015). Yet, this perspective is certainly not mainstream. And, I've only encountered a few individuals who have made this transition to full-time teaching from full-time agency or community practice. I've met even fewer who have done so at a later point in their professional career, with a breadth of experience in community and agency practice. So I share my journey in hopes of encouraging others who are considering a similar transition. I offer observations, insights and recommendations. This is the story of a pracademic.

What is Pracademic?

I choose the term "pracademic" to describe my professional identity. The term pracademic has no clear origin although, interestingly, the term has a Facebook page. A literature review of the term shows its use in several disciplines including public administration (Khademian, 2010), conflict resolution (Susskind, 2013), physical therapy (Coyne, 2007) and criminal justice (Morreale & McCabe, 2011). Some have used the term to refer to a blend of the "practical" with the academic (Lohmann, 2001). Others have used the term to describe a style of teaching that focuses on the practical application of academic theory and knowledge (McDonald & Mooney, 2011). Generally, the term is used to describe an individual or practice that blends practice knowledge with theoretical understanding.

A literature review found no previous use of the term pracademic in the social work literature. However, I think pracademic is particularly applicable to social work education, and by extension, other helping professions. Social work education is a practice-driven profession with a focus on the preparation of professionally trained social workers. Social work education values practice experiences as integral to the curriculum; field education as "the signature pedagogy" highlights this value (CSWE, 2015). Barsky, Green, and Ayayo (2013) found that one of the most pressing needs of social work academic programs are faculty with social work practice experience. Thyer (2000) suggests that social work faculty should be licensed by their respective social work licensing board (which inherently requires social work practice experience).

Hence, "second career" faculty members or pracademics have particularly strong value in full-time social work faculty positions. Social work education increasingly emphasizes practice competencies and behaviors–which practitioners can model and mentor in particular ways. These pracademics bridge practice and academia in ways that uniquely sustain the profession's viability.

Transitioning to Pracademic

This article grew out of my personal experience. I worked for over 25 years in private, non-profit child welfare organizations. My roles included direct care and clinical work, program directing and administration. In my last child welfare position, I administered multiple programs with a combined staff of over 100 and a program budget of over $3 million. I have extensive social work practice experience. I am skilled in understanding and navigating the array of roles social workers must perform in a social service setting.

After extensive time as a child welfare administrator, I decided to pursue my doctoral degree. This decision had three primary influences: First, my life partner is a social work faculty member at a local university. Thus, as the spouse of a faculty member, I was able to pursue my doctoral degree tuition–free. While I still needed to "do the work," pursuing my degree without the added financial burden faced by many doctoral students was a particular benefit.

Secondly, I pursued the doctorate as a personal, academic challenge. I was the only one in my family with a college degree. In many ways, I had already surpassed the academic expectations of my family of origin. However, I wanted to see if I could perform at the highest academic level, including writing a dissertation. Further, much of my doctoral readings and course work benefited me in my administrative role, as I continued working full-time in a social work setting. Additionally, I wanted to place myself in a position to provide leadership and organizational consultation services in semi-retirement; having a doctoral degree would aid that career pursuit.

Finally, and most importantly, I was looking for a new professional challenge. My work was meaningful and I was having a positive impact on the lives of children and families. I particularly enjoyed mentoring new employees. However, I felt the need to branch into a different area of social work. Through my life partner, I was familiar with the social work academic setting. I attended several academic conferences and I taught several courses as a part-time, adjunct instructor. Further, many of our friends and professional colleagues were in academia. Thus, I had an "insider perspective" on the academic and university setting. In many ways, for me, moving from a social work practice setting to an academic setting felt like a natural career progression and mirrored Fox's (2013) assertion that "social work teaching is one form of social work practice" (p. 6).

After completing my doctorate and consulting family, friends and colleagues, I decided to pursue a full-time social work faculty position. While I felt prepared and ready to take on this new challenge, I was not prepared for how difficult it would be to secure a full-time teaching position. I cast a wide net as I looked at faculty position announcements and networked.

Being in a two-career relationship placed limits on how far geographically I wanted to pursue a position. However, my partner and I were open to relocating, if both of us could find acceptable positions. Further, my difficulty in securing a full-time faculty position was compounded by my search occurring in 2008-2009, during the economic recession.

After several phone interviews and campus visits, I accepted a one-year visiting assistant professor position at a small private university approximately 300 miles away. I commuted weekly to this position and, as much as possible, immersed myself in faculty and campus life. Like most new faculty members, all of my courses called for extensive preparation while also continuing my research and scholarship. And, while both a personal and professional challenge, the experience confirmed my decision to make the transition to full-time teaching.

After that one year appointment, I secured my current tenure-track faculty position at a university within a one-hour commute. The position is at one of the three branch campuses of a midsize state university. In addition to carrying a full-time teaching load, I am essentially a site director for the social work program at the branch campus location. I am the only full-time social work faculty member at this location. My current department director and faculty colleagues have encouraged and welcomed me to the department. I have been able to use my previous social work practice experience in the classroom and I have collaborated with a number of colleagues on research and scholarship projects. To a great extent, my department director and colleagues recognize and value my extensive background in social work practice. The students appreciate the real life examples I bring to my teaching and the particular mentorship I am able to provide as they progress toward a career in social work.

Observations of a Pracademic

My transition from practitioner to academic was not without its risks. Yet, initially, the risks did not seem any more so than any other career change. Moving from a full-time social work practice setting to a full-time academic setting provided some unique challenges and rewards. Below, I discuss some observations and insights into the move to the academic setting, and into establishing myself as a full-time, contributing member of a social work department.

The Risk is Worth it

When I announced to professional colleagues my intention to transition to the academic setting, some noted that they saw me as a “good teacher.” However, I was met with some skepticism and concern. This apprehension was compounded by my decision to take a one-year, visiting professor position with a 300–mile weekly commute. Looking back, it was a risky decision. What if my contract was not extended beyond the one year? What if I couldn’t find another teaching position? What was my backup plan should I find myself unemployed?

One evening, my partner and I shared with close friends our decision for me to take the one-year teaching position. After a brief period of silence, one friend said, with a tone of trepidation, “What are you going to do?” Our friend’s question was a genuine expression of concern about my partner and me being so far apart during the week, and my long commute to another state. Later, while talking to her sister, my partner’s brother-in-law asked to talk with my partner. He made sure that my partner had his mobile phone number and said, “If you need anything while Larry is out-of-town, you call me. I’ll be there.” These heart-felt offers of support were reassuring. It also reinforced the idea that many of our friends and family members were questioning our decision to go in this career direction.

As with most decisions in life, this decision had potential risks and rewards. Becoming a pracademic has its challenges and opportunities. My experience with the transition proved to be one of the best decisions of my career. In the following paragraphs, I reflect on what I learned and offer some suggestions from my experience, while honoring that all experiences are unique.

In pursuing that first full-time faculty position, it was important to be flexible. In my experience, hiring practices at many colleges/universities favor hiring young, newly-minted doctoral graduates. Perhaps this favoritism toward younger faculty is a subtle form of ageism. Regardless, many universities may not want to “take a chance” on someone who is outside the normal paradigm of a fresh doctoral candidate. As I experienced, one may need to take a position that is less than ideal.

Networking is key. Identify one or more colleges/universities of interest and develop a relationship with the department chair and faculty. As I share with my students, most social workers obtain their positions through networking and personal connections, not job advertisements. The same is true for academic positions.

When I was applying and interviewing for faculty positions, I was surprised that my extensive practice experience seemed to hold so little weight. Search committees seemed to only consider academic criteria (e.g., scholarship). As a recent doctoral degreed professional, my curriculum vitae seemed to be viewed the same as other applicants with very little practice experience. I thought, and still believe, applicants for faculty positions with extensive social work practice experience should be given greater, or at least equal consideration, compared to other applicants. I advocate that search committees for social work faculty positions provide greater balance. They should acknowledge the different, yet equally important, perspective and resources that pracademics bring to social work education and the faculty role.

Finally, don’t be intimidated by the academic setting. As I’ll discuss in the following section, my experience was that academic culture is different than the work culture in most social work settings. Having a strong, accessible mentor can ease this adjustment. Adjusting to the academic setting is similar to adjusting to any new work setting. One must learn the history of the organization, familiarize oneself with the written (and *unwritten*) rules, and build relationships with colleagues and stakeholders.

Academic Culture

Although I had observed my partner’s experience in academia, I was not quite prepared for the unique characteristics of academia. Here is an incident that encapsulates the nature of academia: After the first faculty meeting for my current position, I saw how we could improve the screening and acceptance process for applicants to the social work program. This suggestion stemmed from my extensive experience in hiring, supervising and retaining many, many employees. I mentioned my idea to the program director; she suggested I bring it up at the next faculty meeting. At one point in the next meeting, I leaned over and asked the program director about bringing up my idea and suggestion. The program director indicated that we needed to conclude our discussion on the current issue. I thought we had already concluded the discussion! I was accustomed to meetings that involved making decisions and enacting those decisions. I failed to recognize the culture of extensive processing that I have since learned is an integral part of academia.

Finally, after 20 minutes of additional discussion on the previous issue, the program director asked me to share my idea. I outlined my thoughts on how we could change the application procedure, thus streamlining the review process and reducing faculty time in admissions meetings. Two senior faculty members immediately stated they did not like the idea and wanted to keep the process the same. Notably, five years later, I brought up the identical idea in a faculty meeting. The idea was enthusiastically accepted and implemented with little discussion or debate.

As stated earlier, in my experience, academic culture is different in many ways than most practice settings. Faculty have a reputation of excessively processing issues and concerns. Further, a “pecking order” must be respected. According to the *unwritten* rules of academic culture, I, a junior faculty member, had no business making such a grand and sweeping change to the admissions process.

Additionally, academia gives inordinate attention to the promotion and tenure process. It seems, at times, little else matters. Thus, faculty are focused on their research and pursuing publications. At the end of each semester, faculty anxiously await the release of their course teaching evaluations. The results of these course evaluations often have a strong influence on whether to recommend a faculty member for promotion and tenure.

As a result, a culture of individualism and insecurity permeate academia. Faculty are often pursuing their individual interests and activities, all in pursuit of tenure. This individualistic focus can be an adjustment for pracademics who, in practice settings, are often accustomed to working in teams.

However, one can pursue tenure with a more corporate orientation. During my first semester, I was assigned a faculty mentor from a different department. At our first meeting, he brought up the issue of promotion and tenure (Did I mention the inordinate focus on tenure!?). To my surprise, he stated, “You do not have to get tenure alone.” He went on to suggest forming one or more writing teams and to always be working on multiple research projects. I found this advice and approach particularly helpful.

Fortunately, my life partner and I collaborate professionally very well; likewise, I have other writing teams that I have found to be helpful. To all new faculty, but especially pracademics, I recommend finding colleagues with whom you have similar research interests. Develop some research projects and submit multiple manuscripts from the research for publication, even rotating first authorship on the manuscripts.

Finally, many faculty are anxious about the promotion and tenure portfolio. As a pracademic, I pursued the portfolio in a manner similar to writing a grant proposal or utilization report. I actually found the process enjoyable, because it utilized many of the skills I honed during my social work practice career. Writing my tenure portfolio gave me an opportunity to highlight my accomplishments–similar to process and program evaluations I had done for grants and other agency performance reviews. I utilized bar graphs, spreadsheets, and data reports–in a manner similar to my role as a program administrator. I gained particular satisfaction from accentuating my accomplishments as a pracademic. In this small way, I hoped to contribute to paving the way for future pracademics. My department head provided my portfolio to other faculty as an exemplar, commenting that my portfolio was exceptional in its organization and clarity.

The Pracademic Journey Continues

It has been six years since I made the move to academia. I’m well established in my role and am a fully contributing faculty member. I have the respect and support of administration, faculty, and students. As I reflect on my current status, I ponder the question “What exactly do I do as a social work educator?” The traditional response to this question would be: I have a triple-faceted role that includes teaching and advising; pursuing a research/scholarship agenda that contributes to the social work body of knowledge; and contributing university and community service.

While the previous response is an accurate summary of the faculty role, I think it is limiting. Instead, I see my role as helping people make their dreams come true. Thus, I help students pursue their dreams of obtaining a college degree and becoming a social worker. By contributing to the social work body of knowledge through research/scholarship, I create conditions that help individuals, families, and groups pursue their dreams of reaching their highest level of functioning and well-being.

This orientation toward dream-making flows from my identity as a pracademic. As a social worker in child welfare practice, I focused on creating conditions that enhanced and empowered clients in reaching their highest level of functioning and well-being. As a social work administrator, I provided support, resources, and encouragement to the staff with whom I worked as they met clients' needs. Now, as an academic, that same focus is transferred to students, the community and the social work profession.

As reflected through formal and informal feedback, I see that I am having a positive impact on the professional development of social work students. In my teaching experience, students perceive my practice expertise as "real" social work education; students comment that they appreciate the practical examples and experience I bring to the classroom. I make connections between practice, research and theory in ways that students experience as grounded in the "nitty-gritty" of social work. Faculty members with substantive practice experience should be recognized by the academy for the particular knowledge and skills they bring to the educational experience.

Likewise, I have found my previous staff supervision experience to be particularly valuable in academic advising and dealing with students concerns. Many of the same skills I used in supporting and mentoring staff members were transferrable to working with students in the academic setting. On several occasions, when dealing with a student concern, other faculty members seemed particularly stressed by the situation and were, in my opinion, overreacting to the concern. I was able to skillfully address the concern with the student in a calm and proactive manner that was aided by my previous extensive experience in staff supervision. This example is one of many ways pracademics can bring particular value to the academic setting.

I find the academic role to be extremely rewarding. I have a positive influence on others through teaching and advising students. Further, I pursue research that both interests me and taps into my knowledge base and expertise. After years in the social work field, it is exciting to see in a more vivid way the connection between theory, best practice, and the concrete application in the field. As an established pracademic, I hope to further develop relationships with community partners that bring this integration of the theoretical with the practical to the community setting.

Looking back, I wish my practice had been more integrated and better grounded in current social work theory, knowledge and best practices. Although I had excellent faculty in my educational preparation, I recognize now the particular value of having faculty who bring extensive agency and community experience. When I say to students they need to develop a certain skill, understand a particular theory, or grasp the importance of policies, they know I have 25 plus years as an administrator. They know that I am the "real deal." I hired, supervised and terminated people just like them. I planned, implemented, and evaluated programs like those where they work. Uniquely, I translate the "book stuff" to the day-to-day practice. My leadership in the agency sector transfers into the classroom context.

As a pracademic with administrative experience, potential leadership opportunities in academia are a possibility. I am fortunate to have strong administrative support (i.e., BSW director and department head) who consistently acknowledge how my practice experience enhance my faculty role. I was even nominated by my department head (and I was selected) for a faculty-as-leaders training program, which identifies and supports faculty for possibly moving into academic leadership roles. However, I have learned that, according to academic culture, appointment to academic leadership positions typically requires tenure.

Have I mentioned the academic fixation on tenure?

Conclusion

My story as a pracademic mirrors other pracademics' experiences. When I present on this topic at professional conferences (Owens & May, 2011) or even use the term informally in conversations with colleagues who have moved into academia after extensive agency or community experience, people respond strongly. They are relieved to know a term to describe their experience. They eagerly share their stories, which have echoing themes.

The pracademic's challenge of incorporating into the academy is outweighed by the contributions they make to social work education. Like other fields (Coyne, 2007), "career switchers" bring particular expertise and real-life perspectives that inform their teaching and enrich the learning experience for students. Nothing substitutes for the pracademics' understanding of the detailed operation of social work practice settings, which is knowledge they gained from years of social work practice experience.

Pracademics bring substantive experience and expertise to the faculty role. Recruiting, supporting, and sustaining second career social work faculty contributes to "developing an educational environment that promotes, emulates, and teaches students the knowledge, values, and skills expected of professional social workers" (CSWE, 2015, p. 15). As a practice profession, social work education must engage pracademics. The recruitment and selection of pracademics for full-time faculty positions not only addresses the shortage of qualified applicants for faculty position (Anastras & Kuerbis, 2009; Mackie, 2013; Zastrow & Bremner, 2004), but achieves greater balance and expertise within the academic department.

For the pracademic, the risk is worth the reward. From my experience, my current role as social work educator has been one of the most rewarding periods of my professional career. I am able to leverage my extensive experience in the field to mentor future practitioners and mold the knowledge base of the profession. As more of us enter the academy, we will pave the way for other pracademics. Our presence in the academy provides unique value to the faculty constellation and the academic culture.

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That's What a Social Worker Does

Dana Davis and Patricia Park

Abstract: This article describes the frustrations of navigating the healthcare system as the daughter of an ill parent, rather than through her role as a professional social worker. Having tried to gain a sense of safety in what seemed to be a most unsafe situation, particular attention is focused on interactions with social workers and whether my personal experience in that role, in a very different venue, was a help or a hindrance.

Keywords: Client centered

My dad was finally home, safely asleep in his bed after a 21-day hospitalization. As I sat there beside him in the darkening room, I thought back to the story a doctor told at a conference I had recently attended, and how it had so directed my focus to the aspect of safety.

In the story, the physician's teenage patient was in labor, and her very large and anxious family was rather disruptive with their constant questions, challenges and concerns about the pain she was having. After explaining the several options for anesthesia, the dad adamantly rejected the idea of an epidural because he feared putting a needle in her back would cause paralysis.

After careful discussion and explanation, the patient herself, elected the epidural, which was quickly and easily administered with the expected result of her being in much greater comfort. When the doctor stopped by later, only three of the original 10 family members remained. She asked the dad where everyone had gone, and he explained that they all felt they could leave because the girl was safe and didn't need their protection any longer.

This story resonated strongly with me. During his time in the hospital, frightened enough for his precarious health, my family and I rarely felt safe. We were constantly worried that we had to be physically present to protect my dad from a system that seemingly would not.

My dad is a white, upper middle class male with one of the best and most expensive health insurance plans available to anyone in this country. He is certainly not a person who has to worry about getting optimal health care or facing the barriers of disparities or discrimination. Nevertheless, my dad and our family could not escape the sense that the health care system was fraught with issues that caused great concern for his safety at a time he was the most vulnerable.

I have been a social worker for 17 years and admittedly hold my discipline to a much higher standard than I do the rest of the health care system. No other health care provider's job description is mandated in quite the same way as by the core values of social work: service, social justice, dignity and worth of the person, importance of human relationships, integrity and competence (NASW, 2014). And yet, while I could certainly speak to the ways the MDs and other health care providers disappointed me and my family on a daily basis, it is for this particular reason I was so dismayed when I encountered the uncaring, unhelpful responses from social workers in my attempts to negotiate with the health care system for my dad.

Social workers should rise above the system and provide empathy, caring and support; it is our job to provide health care in a different way. We pursue change for vulnerable populations and do not stand by as the status quo creates barriers. Social workers emphasize the importance of relationships and a therapeutic alliance that above all shows clients that we care about them and empathize with their situation, even if we can't fix their problem. Social workers know the rules of the health care system and advocate for change; we ask for things that other health care providers wouldn't expect anyone to ask for because we know that challenging these systems is what will put the wheels in motion for positive change in the future.

However, I must also recognize that the venue I have worked in all these years may be different from that of a hospital social worker. My experience is in small, grassroots organizations that emphasize clients' rights and social justice, aligning perfectly with the mission of social work. Being a social worker in a large hospital system likely means that you are facing a bureaucratic system that has explicit rules that state the patients' needs come first–while maintaining implicit rules that we must be able to bill for services, meet the needs of an overwhelming caseload, and follow an unwritten hierarchy that the doctors' opinion is the right opinion. A hospital staff follows the medical model wherein diagnosis reigns: a health care provider imposes their opinion on the patient, and tells them what is wrong with them and what must be done to fix it.

Social workers believe in assessment in which both the client and the social worker work as a team to formulate what the problem is and how to work on goals they set together. This is rather incongruent with the hospital's top-down hierarchal decision-making process. For me to expect hospital social workers to be in constant rebuttal of their co-workers and the system in which they work was likely unfair. As I think back to the situation, I can see that my concern for how my dad was being treated was not only about my mistrust of the system in general, but was reflective of my feelings about how health care should be, rather than trying to work within the realities of how it is.

In the ICU

Even though my family had been sitting bedside with my dad in the ICU–sometimes all night and all day– we were not able to talk to a doctor for more than a minute at a time, and certainly not all of his doctors altogether.

One big concern was his evident cognitive decline. He was often so confused that he didn't know me from anyone else there, eyes wild with panic of the unknown. On one of his better days, we were watching TV together. My dad knows all sports better than anyone else I have ever met, and tennis was one of our favorites to watch together because I had played in high school. He didn't look or sound any different to me but he said, "Look at Venus, she's doing better than the rest of them and she doesn't even have a racket in her hand." I started to question him more closely, and to an observer who didn't know my dad, it really just sounded like he didn't know much about tennis. Anyone who did know him, however, would know that something was seriously wrong. I tried to no avail to help his physicians understand that he had become confused, but because he knew where he was and what the president's name was, they did not address my concerns until his confusion was much worse.

Most of my dad's 21-day stay in the hospital was in the ICU where he was hooked up to many machines, unable to move about on his own. He was growing increasingly frustrated and uncomfortable, and was becoming more and more debilitated. The ICU's devices breathed for him and monitored his condition closely, but we would never get closer to an actual diagnosis or treatment for him. He came out of each ICU episode weaker and further from his 65–year–old baseline.

The first time I actively sought assistance really stemmed from my faith of the social worker's advocacy for the whole person. I felt the physicians were not talking to my dad–or to us–about what was wrong with him and what they were trying to do to help him. He had been in the hospital for 10 days and we didn't have a diagnosis nor an intervention yet. Often their answers were that "the other team is working on that." To them, it seemed, he was a kidney, a lung, a heart. Family members of patients in the ICU need information about the patient's condition that is clear and understandable. The way they receive the information is equally important. The environment itself is so overwhelming and it needs to be discussed in language that allows for a mutually respectful relationship between the family and the healthcare team (Auerbach, Kiesler, Wartella, Rausch, Ward & Ivatury, 2005). It has been documented that patients feel most cared for and secure when doctors avail themselves for consultation and demonstrate ease with family members (Bendapudi et al., 2006). A multidisciplinary team approach is recommended; it is easier and more effective to speak with a cohesive team rather than numerous individual specialists (O'Daniel & Rosenstein, 2008). We really needed that conversation with his team of doctors, or at the very least, just one doctor who could present the whole picture from the team.

I was perhaps excessively worried that if we asked other health care team members for this meeting that we would be judged as nagging and intrusive. At one point, my sister had asked a follow-up question to the pulmonologist, who on several occasions had informed us that he was not only the lead person taking care of our dad, but was also in charge of the whole ICU. In response to her question he said, "I don't have time to explain advanced biology to you."

This was off-putting, intimidating, and well out of the realm of the ways a patient wants to have communication with their doctor–up to and including their ability to reduce medical jargon (Bendapudi et al., 2006). Fortunately, my sister did not back down, and let him know he could go ahead and give his answer a shot, and that she would muddle through the advanced biology on her own. Probably this would have been the time to remind him that:

> "It is the patient who carries the burden of illness, but the compassionate physician shares that burden, lifting it when possible and lightening it when that is all that can be done. This sharing of the burden has always been the hallmark of the medical profession." Richard S. Hollis, MD (Bendapudi et al., 2006).

Doctors' Orders

Though the numerous nurses I met over the twenty-one day period greeted me with varying levels of kindness, there was one consistent theme that I received from them: the doctors put the orders in and the nurses follow them. Evidently, there was little wiggle room for them to make independent decisions about my dad's personal care, and they seemed generally disinclined to question doctors' orders or advocate for a different opinion.

The best example centers around my dad's oxygen requirements. With each nursing shift change came the constant battle of them noticing that my dad's oxygen levels were low and turning them up. I told them that at increased levels, we consistently noticed an immediate decline in his cognitive abilities, including his ability to communicate. Each time I was told that this is standard protocol for a healthy oxygen level for patients.

It took the physicians a long time to figure out, and then write the appropriate orders for the nurses: that in my dad's case, low oxygen readings did not require more supplemental oxygen. His body could not handle it. I would try to be there each time to ask them to refer to this order more closely while I personally turned down the oxygen dose until they figured it out. This failure of team communication is the most common form of medical errors in hospital settings and is now the third leading cause of death for Americans (O'Daniel & Rosenstein, 2008). The combination of knowing this and my dad's significant mental status changes was so completely unnerving that it made me fearful of everything. I was afraid that I was wrong and that I was making him sicker by intervening in ways that were well beyond my scope of practice. However, my experience with my dad made me feel as if I was right–which made me even more scared. I didn't want to be right. I wanted the health care providers to be right so I could go home and leave them to their job. If I was right and they were wrong, then I had to take responsibility for something that I was not trained to do: basically trying to take my dad's life into my own hands. I felt, and it was confirmed by several events when I wasn't there, that if I left, these details would go unnoticed. I would feel such panic over leaving and would plead with each nurse to make the instructions clear that my dads' oxygen requirements were different from the standard protocol. Sometimes I left feeling relatively assured that the nurse had listened to me, rather than merely having heard me. Usually, I was placated with, "Yes, of course, you don't need to worry. We'll make sure we take care of him while you are gone. You go home and get some much needed rest."

I regularly tell patients that they don't have to worry about something any longer because it is my job to worry about it. Helping patients reduce their worries either by my taking on a role that would reduce their burden, or by explaining things in a more easily understood manner, is a consistent theme in my work. Patients tell me daily that they feel so much better or are less worried after talking to me, which is form of self-reported evaluation I have received over the years to tell me that my services have some value to patients.

But when the nurses told me not to worry, I didn't feel as if they were taking care of it: I felt like my not being there meant that things could go wrong, and they did when the doctors didn't change the oxygen level orders or the healthcare team didn't notice the change and they would subject my dad to oxygen levels that his body could not handle. I would repeatedly come in the next day and find him in a worse cognitive state, again threatened with returning to the ICU again or remaining in the ICU for longer because the standard protocol was being followed for my dad when he required an exception. His individualized needs were not being met in a system that relies on the routine procedure.

Connecting to the Social Worker

These experiences inclined me to direct questions to the social worker. Part of the job of the social worker is to help people feel that someone is advocating for them, and by virtue of this, it seemed that at least the social worker would be "on my side." I understood the difficult position I was asking her to walk into. Still: it was important. With the social-worker-as-advocate premise firmly in place, I asked her to please help coordinate my request: That the doctors talk to one another, get consensus about what my dad's overall status was, then have one of them sit down and talk to us.

Almost as soon as the words started to come out of my mouth, I sensed her resistance; she appeared to feel trapped and filled with dread, her eyes darting back and forth as if looking for escape. She told me this was not a reasonable request, and would not agree to advocate for us. Her tone of voice indicated her incredulity at my presumption. The best she could do was to make a note in the chart that the family would like to talk to the doctors. I was furious, and felt unsupported and out of control. Later the next day, one of dad's doctors came by and said that he understood that we had questions. My stepmother and I were allowed about five minutes to voice our concerns. It was the last time we were given this opportunity, and my dad was there for another 11 days.

When the doctor left, we still did not have a diagnosis, an intervention, nor a change in medication. We were still met with the answer that other doctors knew more about this or that, and that we would have to speak to each of them individually. I did not ask to see that social worker again, and she never checked back with us to see if we had gotten the answers we needed.

I asked for a social worker's assistance a second time regarding discharge planning. I was worried that the doctors would suddenly decide that my dad could go home, and that the staff would not have time to get all the things he needed to be there, necessitating transfer to a nursing home instead, something that regularly happened in my own work. I asked the social worker if she would start working on durable medical equipment (DME) and home care referrals. She was very pleasant and told me she would take the list down to my mother to select which DME and home care agencies she wanted to work with. Although I understood that she was rightly trying to assure self-determination, I told her that she could select those for us because we did not know one from another, and would gladly rely on her expertise to select one. She told me that due to patient choice she would not be able to select for us; we had to do it. I explained that my stepmother had been feeling particularly overwhelmed by all the decisions she'd had to make: whether my dad should go to the ER or not, whether he could come home safely or not, whether he was going to live or not. She went back and forth with me several times, despite my request that my stepmother not be handed this additional decision-making stressor. I felt as though she was deliberately not hearing me, insistent that she would not be able to choose for my stepmother, and offered no other solutions. I quickly called my stepmother to forewarn her and stayed on the phone, acting as a buffer between her and the social worker as the process ensued so that the social worker wouldn't upset her as she had upset me. Family members have been found to actually experience acute symptoms of PTSD during ICU hospitalizations, especially when they were the primary decision maker, as my stepmother was (Azoulay et al., 2005). I wanted to protect her from as much additional distress as possible.

The third incident occurred around a piece of DME the doctor had ordered for home. It was not just any piece of DME; it was a breathing assist machine, otherwise known as BiPap, which my dad had been wearing ever since he came off of the ventilator in the ICU. The physician told our family that he would have to wear it 24 hours a day or he would die. I contacted the new social worker on that floor to give him a heads-up on what my dad needed so it could be arranged in a timely way. The social worker explained to me briefly that it might be hard to get; I told him I'm sure he would work it out.

A little later my stepmother called me in a panic; the social worker had told her that dad's insurance wouldn't let him have the equipment. She wanted to know what were we going to do, and though I had no idea, I told her I would take care of it and not to worry. If he needed it, he would get it.

Ultimately, the doctors decided my dad would not need the BiPap after all, but my stepmother remained stuck on what the social worker had said to her: that he wouldn't get it because it wasn't covered. I found out later that no one's insurance covers this without having outpatient testing in the form of a sleep study to confirm need. There is some small comfort in knowing that this is how it is for everyone, and that they most likely wouldn't do it that way if people were to die before they got the machine. The point is that no one, including the social worker, explained it to her in that way. What the social worker did not tell her was not to worry, that he would check, that there might be other issues involved that he was not aware of but would look into.

So What does a Social Worker Do?

One day, my stepmother asked me: "What exactly does a social worker do?" She didn't really know the details of my work. She had always heard me say such positive things and had assumed that what social workers do is a great thing. While she had been ruffled by all of my dad's health care providers at one time or another, she had been especially upset by the social workers, as had I. Our experiences were not what any of us thought they should have been. We did not feel comforted. We did not feel supported. We did not feel like someone was advocating for us. We did not feel empathy or validation. We did not feel as if our concerns were being heard.

The social workers told us that we were being unrealistic. They told us that we had to adhere to patient choice about something we did not care to choose, and we were not offered the choice of not choosing. We were told that we would not be able to get equipment the doctor had ordered and said was life saving, and were offered no understanding or other options. Time and time again our experience with the social worker left us more upset than the frustrated reasons we came to them for in the first place.

A Little Knowledge…

I still wonder whether my 17 years of experience in the health care system was an asset or hindrance. Perhaps if I had asked a nurse they would have acted more appropriately. Perhaps my knowledge of how our systems could make such a reasonable request seem ridiculous made me more tentative in my asking, and therefore more likely to meet resistance because of my hesitation. Perhaps the way I, and my colleagues, work in our own particular social work milieu was a unique experience that I should not have expected from other health care providers. Perhaps because I already understood the systems, providers were less likely to advocate for me because they knew that "I should know better," and would have been prepared for the expected negative outcome.

All healthcare providers are potentially susceptible to compassion fatigue, vicarious trauma, and burn out. It comes from being on the cumulative receiving end of patients telling them stories of trauma. Symptoms of these conditions include a lessened sense of safety, control, identity and ability to trust (Bloom, 2003). Perhaps social workers, who are trained to be empathic, client–centered, and collaborative in their approach to patients, are more likely to burn out after being placed in a system that is incongruent with those philosophies. This is not only from patients but the very systems they are required to work within. I myself have certainly experienced periods of exhaustion from fighting the good fight against systems and later realizing that I have less personal resources left available for the families in front of me.

While I knew that it was fair to advocate for my family–and to expect the social worker to not only stand alongside me, but to take the burden for me–I can see that it is yet another barrier that they face with few resources or collegial supports. Based on limited time constraints, I imagine that it might be realistic for them to put me and my family at the bottom of the list, knowing that my family had me to navigate the system for them, when most patients had no one with those skills and resources to offer their patients.

When it works

The fourth and final experience with a social worker was with someone that I did not contact proactively, but who came and introduced himself to my stepmother when my dad was transferred to a non-monitored bed. This social worker assured my stepmother that he would order all the supplies that she felt they needed for the home and anything the doctor felt was needed as well. He set up a home care agency and an oxygen supply company and came by from time to time to check in and update the family about what was going on over the next several days. On the day my dad was being discharged he came in to fit my dad for the new walker he was supplying us before we left the hospital. My dad rose out of bed to stand next to the walker and promptly passed out right back onto the bed. Of course, we were all in a panic, and though the medical staff took care of him quickly and there was no injury, the social worker stayed in the room and helped my mother and I stay calm. We had assumed he had a seizure, as we had never seen anyone pass out before, and we were more upset than we realized. The social worker stayed long past when all the other clinicians had left the room. With the discharge canceled, my stepmother inquired about what she would have to do to cancel the home care and oxygen people that had just called to confirm they were coming to the house. The social worker said that she didn't have to worry about it; he would take care of it and reorder them when it was time for my dad to be discharged again.

We felt soothed and relieved after every encounter with him. We didn't have to interrupt him to tell him what we were worried about; he was actively listening to us. We did not have to track him down, as he was sure to regularly check on us and inquire as to our needs. We did not have to convince him of our concerns; he was clearly on our side and would proceed with our requests and advocate for my dad's needs. He was empathic, validating, supportive and caring: He was a social worker.

Our experience with him was the first time we had felt safe during the 21-day hospitalization. He did not necessarily have more knowledge, ability or resources than the other social workers or any of the other health care providers we faced; he simply tried harder. He treated us like human beings, perhaps how he would like himself or his family members to be treated.

Other health care providers are often confused by social workers' roles in our systems. We do not diagnose problems; we assess clients' strengths and resiliencies. We do not prescribe treatments; we give support in building a plan that is based on clients' goals that are realistic, measurable and achievable once they leave the health care setting. They need to be able to implement these interventions into real world settings. If clients feel different, safer, when working with a social worker, it is because we do our job differently: we find out what the individual's goals are and we help achieve them. This is teamwork between the healthcare provider and the patient. This is being client–centered.

Sadly, being client-centered is not congruent with the top–down hierarchy of the medical model. This is not typical of healthcare systems today, and part of why it is hard for social workers to do their jobs in the existing environment. Have some social workers adapted to this culture rather than trying to change it? The history of social work is based on changing the status quo and fighting for social justice. Social workers in complex institutions such as hospitals have to keep this at the forefront of their job even when it seems in total disregard for the rest of the health care team's approach.

Social workers have to make an extra effort to implement other mandates of their profession –advocacy and social justice while continuously working to make a safer and more effective experience for all clients and health care providers. It can be done. I've personally seen it work for my dad and our family.

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Campaigning for Social Justice: Increasing Public Access to Professional Social Workers

Raymie Harvard Wayne, Christine Limone, and Stephen A. Karp

Abstract: From 2011 to January 2014, the Connecticut Chapter of the National Association of Social Workers (NASW/CT) embarked on an unprecedented and ultimately successful campaign to change state hiring practices so that clients of state agencies would receive services delivered by professional social workers. Just as clients of private agencies receive care by professional social workers, so should recipients of public sector social services. It is a social justice issue. This reflection presents that campaign from the perspectives of three of the many key players who were instrumental to its success.

The main characters in this narrative are Stephen Karp, NASW/CT executive director for more than 20 years; Christine Limone, NASW/CT newly hired political director, and Raymie Wayne, chapter president from 2012 to 2014. Highlights of our thinking processes include the strategic public relations decisions and the fine judgment calls in community organizing practice that are often over simplified in textbooks.

Steve: As a community organizer, looking for a window of opportunity to change a bad policy is as instinctual as a trick-or-treater looking for candy. It is what you do. The largest window of opportunity of my career swept in with the 2011 Connecticut Gubernatorial election. For 22 years, I had been responding to calls from NASW members every time the title "social worker" was misused in the media. Sure, I wrote letters to the editor and targeted recidivist reporters to educate the media and the public about real social work credentials, but it was repetitive, never ending work.

Asking reporters to use the title "case manager" for non-degreed workers was Band-Aid advocacy, it was a temporary correction that did nothing to improve service delivery. The real cure would be to have credentialed social workers provide the care offered by the state. I believed our new Governor, who we had supported during his campaign, would be approachable. I therefore planned to ask him to change the state hiring practices so that professionally credentialed social workers were in state social work positions. Radical idea, I know. If successful, this could be a win on many fronts: consumers of state agencies who are among the state's most vulnerable residents, would receive care by real professional social workers, social work degrees (BSW and MSW) would be recognized and valued, and media reports about state social workers would reflect the work of real social workers!

If We Don't Do it, Who Will?

Steve: My first step was to gain buy-in from the chapter's Board of Directors for a campaign that was going to be heavy on resources (especially my time). Though the board is responsible for major policy decisions, it was not unusual for me to bring initiatives and recommendations to their attention. In practice, this is how most boards and their directors operate (Hardcastle, Powers & Wenocur, 2011, p. 230). I recall telling the board that at best we had a 50/50 chance of success. I was elated when after some discussion, the board voted to support a campaign. I noted, however, that at least some board members misunderstood the campaign as a title protection effort, which would simply require that the state (and others) refrain from calling non-degreed employees social workers. Instead, I was proposing that we get the state to hire only degreed social workers. It corrected the misuse of the title by changing the practice to match the language, not the language to match the practice.

Raymie: I was a member of the board and Executive Committee, and was running for chapter president when Steve brought the idea of the campaign to the board for discussion. Steve had distributed a detailed memo outlining his rationale for such a campaign. He supplemented his memo with a verbal presentation at the meeting, including the anticipated resources and likelihood of success. In my memory, the campaign had been presented as something that would require a lot of effort, some fiscal resources, and would most likely be unsuccessful. It is interesting to see that Steve recalls reporting a 50/50 likelihood of success.

At the board discussion, I was among the first to speak. My first thought, and my statement to my board colleagues was, “if we don’t do this, who will?” Even if we were not to be successful, it was most definitely our fight. I also thought that success was not an all–or–nothing proposition. There could be little wins along the way that would justify the effort. In the discussion, I noted that even if unsuccessful with regards to the ultimate goal, surely the effort would improve social work’s public image. Though it was presented as a risk, I could not see a downside. Others spoke as well, some suggesting they thought we were seeking title protection. In the end, there was a unanimous vote to proceed. We ended the meeting with enthusiasm and hope for the future, with no idea of what was to come.

The Data Dilemma

Raymie: Our first challenge was to find research that would support our contention that the social work degree makes a difference in the quality of services delivered. I recalled seeing research years back that degreed social workers had lower rates of burnout than their non-degreed counterparts. However, there was minimal research available, and what could be located was contradictory, out–of-date, or narrowly focused on child welfare, rather than state systems as a whole. Though some of the child welfare research was helpful, our campaign spanned all state agencies and services. As we assembled the data, citing articles as far back as 1987, we knew that the older studies lost much of their relevance. Our audience, however, would be unlikely to notice the actual citations. Sure enough, we were never challenged on the sources used for our fact sheets or the data behind our arguments.

The fact that some of the data was contradictory was troubling, especially because we believed our campaign was serving the public good and not just the profession. After all, we were fighting so that low–income residents could have the same access to degreed workers as residents with private insurance. In actuality, the limited number of studies, made it difficult to draw any real conclusions. Reflecting on standards for the application of research, I realized that the studies that found that the social work degree was not determinative of better practice needed to be replicated to demonstrate reliability, and variation to show to the ability to generalize. Ultimately, the balance of the evidence showed that the social work degree does make a difference in the retention of employees, thus impacting the continuity of service delivery. This was all we needed to keep going.

This Isn’t About Title Protection

Christine: My first day on the job as NASW/CT’s political director was October 17, 2011. In the midst of routine “first day of a new job” sort of things, Steve told me that the board had voted to support the “Social Work Public Access Campaign.” The campaign would be a big part of my work with the chapter. Steve handed me a folder to read what the chapter (he) had done so far. The portfolio contained the chapter’s position paper (a document that included a statement of the campaign’s goal, the rationale as to how the goal served the public good, and a summary of the supporting research), and supporting literature with empirical evidence.

As we embarked on this campaign, we would add materials, such as letters of support. In one of my early conversations with Steve, I made reference to the Campaign as “Title Protection.” Steve quickly corrected me. This campaign was not a “Title Protection” campaign – because the Department of Children and Families (DCF) could easily issue all their social workers new ID badges with the title “case worker” and what really would change? No, this was a *competency* campaign. Our concern was about the quality of service delivery and what we would later dub as “end user” outcomes, meaning we sought to impact the quality of services received by the families and children served by Connecticut state agencies.

A central goal of the Public Access Campaign was to impact all social services, statewide. This meant making a change at a central administrative level, rather than through each administrative office or agency. In Connecticut, the Department of Administrative Services (DAS) manages human resource policies. Specifically, the Personnel Division of DAS has the authority to make the systems changes required to meet our goal of having a fully qualified social work staff serving individuals and families. Lobbying DAS was most certainly an uncommon practice, yet necessary to achieve our change goal.

Like all good CO efforts, attention was not just paid to the decision makers at the top. (Weil & Gamble, *2005). While, as described below, chapter leadership was lobbying DAS, a chapter intern, BSW student Paul Donovan, was organizing social work students from the seven Connecticut social work programs. As the next wave of graduates to be seeking employment in the field, the students were, as Weil and Gamble describe, a functional community with a common interest (p. 130). Paul's efforts to inform and mobilize students paid off in ways that we never could have imagined!*

Preference or No Enchilada

Steve: An important strategy decision was whether to advocate that the state hire only social workers or simply give preference to social workers for social work positions. I knew that preference was more feasible, however, Christine and Paul made a strong case for going for the gold. My deference to democracy (it was two against one) lasted until my first meeting with an important state official who told me point blank that you cannot tell a state agency who it can or cannot hire. From that moment it became a campaign for social work preference in hiring.

One of the things that made this campaign unique and successful was our sophisticated use of strategy. So much of what we did was purposeful, with thought to short and long–term consequences. It was like skipping pebbles in water and trying to anticipate the succession and impact of the skips as well as the rings in the water. For example, we knew that the state employee union would oppose the campaign, as some of their members would be negatively impacted if degreed workers were to have more opportunities than others in the state system. Fortunately for us, the state employee unions were focused on arduous labor negotiations with the Governor. This allowed us to conduct a "quiet campaign" of administrative lobbying. A quiet campaign is not, however, a silent campaign. Current and potential NASW members needed to know what we were doing so they could support the effort and find value in their connection to the association. Ironically, some of our members were also union members. Weighing the advantages and disadvantages, we opted to publicize the campaign progress in the chapter newsletter, believing that those with dual union and association memberships would be supportive of the effort and not raise the issue with the union. We were right. Thus, the decision to use the chapter newsletter to share information about the campaign was an important strategy decision and not something that happened automatically because it was time to publish the newsletter.

Taking the Show on the Road

Steve: A strategy of which I am very proud was our seeking support from non–social work organizations. Because the campaign was about end user outcomes and not social work jobs, it was important to identify stakeholders that were not social workers. Our message would be expected from social workers, but would take on a new meaning when delivered by other interested parties.

To this end, we met individually with representatives from about 15 non–social work organizations that served or advocated for people assisted by state agencies. We asked the agency representatives to sign onto an open letter to the Governor and to write individual letters of support for the State's hiring of professionally prepared social workers. The meetings included Christine the political director, a social work educator, and me, the executive director. This gave us a terrific team. Christine spoke about clinical social work expertise, the faculty member presented the uniqueness of a social work education, and I presented the larger workforce arguments.

In the case of the Connecticut Association of Non–Profits that represents over 500 non–profits I thought NASW/CT should join before we asked for support. They became the eighth organization to sign onto the campaign. We secured support from about two–thirds of the organizations we approached, most agreeing to write to the Department of Administrative Services (DAS) Commissioner on our behalf. We orchestrated the letters to be sent six to eight weeks apart, creating an ongoing reminder of the campaign and the message that we were not going away.

Christine: I think Steve and I made a great road show duo. We played off of one another's strengths very well. After a few meetings we developed a rhythm and had the key talking points down. If Steve usually made one point, but forgot to mention it, I would raise it, and vice versa. I was especially pleased that I could add value to the pitch so early into my affiliation with the chapter. I drew on my practice experience as an agency program director, having had both social workers and para professionals as direct reports. I added anecdotal evidence that supported our claim that professional social workers are better suited to serve fragile families than are paraprofessionals. I used examples of professional boundaries, ethics, knowing when to seek supervision, and documentation skills.

During our visit with one private nonprofit entity, someone asked about the difference between a master's degree in psychiatric rehabilitation verses a social work degree. Because of my past work in psychiatric rehabilitation, I was able to illustrate that the State positions at issue did not involve psychiatric rehabilitation and therefore would not attract candidates with that degree. Steve told me after that meeting that he was glad I was there to field that question because he would not have known how to answer it. As we took our road show around the state, I was not terribly surprised that people with whom we spoke who were professional social workers tended to endorse our campaign but people from relatively close disciplines, who may have perceived our campaign as a threat, did not.

<u>Raymie:</u> As president I did not attend as many meetings as Steve and Christine. The campaign, after all, was their day job. The meetings I did attend have since blurred into one super meeting. What I do remember is feeling that the meetings had a rhythm of their own, and although I am not usually musically inclined, I was able to join in without missing a beat. My role was to talk about the social work competencies and practice behaviors, field education as our signature pedagogy, social work's use of the strengths perspective, our commitment to cultural competence and utilization of the person–in–environment concept. In other words, I presented the uniqueness of social work education. Speaking at the meetings made me proud to be a social worker. At each meeting I was struck by some unique aspect of our curriculum or values, or the way in which it all comes together to be social work.

Courting the Commissioners

<u>Christine</u>: Our early meetings with DAS were not as successful as we hoped they would be. An initial meeting at DAS that included Dr. Karen Bullock (Chapter President from 2010–2012), Steve and myself, led me to believe that we had the commissioner on our side. At that meeting Karen set the stage by looking at the commissioner, pointing to the social work series job description, and saying "all we are asking for is the inclusion of *one teeny little word*... 'preference". The commissioner could not help but return Karen's charming smile. At the same meeting the commissioner sheepishly grinned when Steve pointed out that the job description required "knowledge of social work skills and theories…" Steve asked "how are candidates going to possess the skills and knowledge if they didn't go to social work school?" I thought it was a done deal, and did not expect the stonewalling we later experienced from his department.

We also met with representatives from two of the three agencies that provide the most public social work services to residents of Connecticut. The Commissioners of the Department of Children and Families (DCF) and the Department of Social Services (DSS) both understood the social justice aspect of our concern, recognizing that we were not just advocating for our profession. Despite being concerned about the potentially shallow applicant pool, the Commissioners were prepared to make internal changes within their agencies. I remember promising a DSS representative, "We will work with the schools of social work to make sure your applicant pool is flooded with BSW and MSW candidates".

We were able to respond to all other concerns raised by the commissioners with data. For example, there was the diversity concern, questioning the number of minority graduates. Steve worked with schools of social work to get these data. There was a concern expressed about the applicant pools at the DCF offices in the far corners of the state. We contacted the New York schools that have campuses at the Connecticut border to get the number of Connecticut residents who graduate from their programs to demonstrate that there would be an adequate applicant pool statewide.

<u>Steve</u>: Meeting with commissioners and deputy commissioners was another key component of the campaign. Each meeting was unique and difficult to anticipate. The DSS commissioner, for example, had a slew of staff with him. That meeting was one of our earliest successes, as the commissioner agreed with us and called the DAS commissioner on our behalf. DCF was by far the most interesting as we never met with

the commissioner, rather we had two meetings with two different deputy commissioners. At the first DCF meeting the human resources director said she had a degree in psychology but realized that did not make her qualified as a social worker. I wanted to jump across the table and hug her! As the ultimate change target, I met with DAS representatives most often. One meeting, for example, was with the deputy commissioner, who confirmed that a state agency could make an internal decision to hire only MSWs and BSWs even if the state job specifications allowed other degrees to qualify. Early on, I knew we had a strong likelihood of succeeding within at least one state agency.

<u>Raymie:</u> The fear of a lack of applicants arose at a meeting I attended at DAS with the deputy commissioner. Though I did not know ahead of time that the issue would be raised, it was as though I had been rehearsing all morning. I spoke about the diversity of our social work student body, the maturity of the students in our adult learner program, and of recent conversations with students saying they would be more inclined to apply for positions that explicitly valued their degrees than those that did not. I argued that the State would see an increase in social work applicants if it changed its policy to recognize the social work degree. As the chair of the Social Work Department at my school, I promised to help recruit a qualified, diverse applicant pool for the state positions.

Legislative Role in Regulation

<u>Steve</u>: An important, but perhaps unexpected group that we needed to court were the six state legislators with social work degrees. Though we were seeking a change to state regulations, and not legislation, this group could be very influential to commissioners of state agencies who rely upon the legislature for funding. Two of these legislative meetings were particularly alarming. In one meeting, a legislator was so persuaded by our cause she enthusiastically told her aide to “put it on the legislation list!” This, of course, would have been terrible, as it would have been certain to be unsuccessful and would have made our “quiet” campaign loud. Luckily she became busy with other issues as the session progressed. Another well–meaning legislator strongly urged us to begin with our child protection agency and to work outward from there. This was not the strategy we wanted to pursue. Both were powerful legislators and we chose not to argue with them, but to quietly keep on our intended path.

<u>Christine</u>: The strategy to reach out to social work legislators reinforced my belief in the importance of relationships. Very early in my tenure at NASW/CT, on behalf of the chapter, I reached out to a legislator with whom the chapter had not worked with in some time. This social work legislator had been an assistant to the DAS commissioner. As a new ally of the Chapter, the legislator shared information about the Commissioner’s reasons for resisting our proposal, and offered to speak to the commissioner on our behalf. I originally had reached out to the legislator because I valued the relationship, not yet knowing he would become such an asset to the campaign.

Getting an Education

<u>Steve:</u> I had expected that the schools of social work would be the easiest group from which to gain support, and was therefore not prepared for the amount of time and energy it took to get all of them to officially sign onto the open letter. The program directors needed to seek approval from their upper administration, which I understood, but when it came time to get them to write the individual letters of support I was surprised how few actually did it initially. In the end, it worked out well as some schools wrote letters early on and others did not, so that later when I needed more letters I was able to go to those who had not yet written.

<u>Raymie:</u> When Steve asked me, as BSW program director and department chair, to sign onto the open letter, I thought “of course…. right away!” Lucky for me he made a passing reference to getting approval from above. Apparently the approval procedures at other schools had been slowing the process down more than anticipated. Truthfully it had not occurred to me to seek approval at all. I am lucky that Steve raised the issue, however, as it turned out to be completely necessary that I sought approval. I sent the campaign letter to my Dean, who sent it on to the Provost, who then (much to my surprise) sent it to the CFO for approval… eventually I was permitted to sign onto the campaign. Of course my school’s Counseling Department was unhappy when the Chapter achieved our first success at DCF, creating fewer options for their graduates. Clearly the issue was more complex than I had initially recognized.

The Key Constituency: NASW Members

Steve: The social work community at large was engaged through mobilizing social work students and members. The mobilization effort included speaking to students in social work classes, reaching out to members at chapter events and conferences, and e-mail blasts to the entire membership. We created a separate student petition that contained nearly 500 names. We asked members to write and email the DAS commissioner (not the DCF or DSS commissioners, however, as I did not think they would be receptive to grassroots lobbying). Throughout the campaign I questioned if the grassroots efforts made a meaningful impact on state decision makers, and still do not know, but the contact with members and students sure did give the chapter visibility as working for the profession.

"Would YOU go to a hospital where only 28% of the nurses held degrees in nursing?"

Steve: Two unexpected pieces of news helped shape the next phase of the campaign. In August, 2012, an internal DCF audit revealed that only 28% of the department's "social workers" had degrees in social work. Nationally, 33% of child welfare workers have a professional social work degree, a statistic I always thought was disgraceful. Upon learning of the 28% statistic, I started asking, "Would you go to a hospital where only 28% of the nurses held degrees in nursing?" The message was clear. The second news item was even more shocking, at least for those of us in New England. The Texas legislature, as it turned out, passed a bill establishing a preference for the BSW and MSW degrees when filling child welfare positions. At a meeting with the DAS commissioner, I said "surely we can do as well as Texas". He chuckled, neither of us needing to say more.

Christine: The new tagline, "would you want to be treated at a hospital where 70% of the nurses do not have a degree in nursing?" became a battle cry. We had flyers at our statewide annual conference, sent an e-blast to members (with an easy five minute activist opportunity), and brought the message with us everywhere we went.

The key thing to remember about messaging is to know your audience. For the most part the campaign was about public access to social work services. This meant we deliberately down played the self–serving aspect of this campaign. However, when I spoke to social work students, I played that piece up–"you guys are paying for and *earning* your social work degree. Shouldn't you get preference in hiring for state social work jobs?" That's called speaking into your audience's listening.

Governor Gets the Message: Social Work Matters

Sometimes in the course of campaigns, serendipitous opportunities arise that you never could have orchestrated or even imagined. Such was the case in our Public Access campaign. One spring day, an instructor at the University of Connecticut (UConn) School of Social Work invited Governor Dannel Malloy to speak to her "Political Social Work" class. At the conclusion of his remarks, the Governor took questions from the class. As a result of NASW/CT's intern's mobilizing efforts, students at UConn were aware of our campaign. A student asked the Governor about his position on hiring professional social workers for state social work jobs. As was reported to us at NASW/CT, the Governor said something to the effect of "I don't think you need a social work degree to be a social worker." The Governor then quickly excused himself from the class without taking any other questions. A student who was in the room at the time later reported that both the students and their instructor were dumbfounded by the Governor's remarks. Did the Governor forget to whom he was speaking? The Governor's words, however, traveled quickly.

Christine: The next day at the chapter office, the phone lines lit up. Social workers from all corners of the state were calling in, "Did you hear what the Governor said at UConn?" Connecticut social workers were mad and ready to take action. They wanted to know how NASW/CT would respond. I was almost giddy at this chain of events. As community organizers, we could not have dreamed of such a gift landing in our laps. Steve and I quickly strategized how we could capitalize on this wave of enthusiasm. We decided to launch an impromptu phone campaign. Subsequent callers were directed to "call the Governor and promote the value of the social work degree."

About a month later, Governor Malloy was speaking to BSW and MSW students from Southern

Connecticut State University for their annual Lobby Day at the state capitol. This event had been arranged months prior to the UConn class visit, and again, serendipitously just happened to be scheduled four weeks after the Governor's now infamous appearance at UConn. At this event the Governor seemed to remember who his audience was, and even referenced that he had received phone calls from social workers about the Public Access campaign. Although conciliatory in demeanor, the Governor stopped short of supporting our position.

As I reflect upon this series of events in the campaign, I am struck by what sometimes appears to be serendipitous, may simply be the result of sound planning and solid execution. If it were not for identifying social work students as key stakeholders and tasking our student intern with the job of educating and organizing them, would that student at UConn have asked the Governor his position on state social work jobs? That one question after all, set a much larger mobilization effort into action.

Three Times a Charm: Malloy and Social Work

Steve: We collected over 500 student signatures on the petition, had many signors on our open letter, and had approached just about all likely supporters. I knew it was time to present our case to the Governor.

We invited Cokey Connocanon, an MSW student and DCF foster mother to attend our meeting with the Governor. In addition to our usual pitches, Cokey spoke eloquently about her experiences in dealing with degreed and non–degreed workers at DCF and how those experiences served as a catalyst for her to pursue her MSW. Cokey added the lived experience that focused the discussion on the quality of care, and public access to qualified social workers, rather than jobs for our constituents.

Steve: When we first met with Governor Malloy I was most struck that he did not have any staff in the room with him. I was not sure if this was a good sign, but clearly we had his undivided attention. In the meeting I presented him with our open letter and our student petition. I felt that our presentation went well, that the Governor was listening to us, and that he was receptive to our ideas.

Christine: When Steve told me he had secured a face to face meeting with the Governor to discuss our public access campaign I was thrilled on one hand. Wow! Face time with the Governor to make our pitch; but on the other hand, the announcement caused me some anxiety. Could I use my past association with the Governor to our advantage?

Governor Malloy and I are from the same hometown. Prior to being elected Governor, Dannel Malloy was mayor of our city at a time when I was a community practitioner in town. Over the course of his tenure as mayor, I had several occasions to interface with him in my capacity as an agency program director. On top of that, my father had been the Governor's high school history teacher, facts I made a point of mentioning when I was interviewing for the Political Director position. Now I was a bit nervous, "ok, so I 'know' the Governor. How can I work this angle to champion the public access campaign?"

The morning of our meeting with the Governor at the state capitol, Raymie, Steve, Cokey, and myself were in the receiving area, waiting to be called in. I think we were all a little nervous. A private meeting with the Governor was a big deal. What I once spoke so confidently about in my interview, I found myself downplaying as we stood there. "Well, it's been a couple a years since the Governor and I crossed paths. With everything he's concerned with as Governor, I'm not sure he'll make the connection that he's worked with me in the past."

The door to his office opened and we were invited in. There stood Governor Malloy all by himself, no handlers. He shook our hands one by one. When he came to me I smiled and said, "Hello Governor, nice to see you again." Once we were all seated, the Governor turned to me and said, "How are your folks? Are they in Florida for the winter?" YES! The hometown connection breaks the ice! I remember being so excited that this little exchange happened in front of my boss and the chapter president (*see, I told you I knew the governor*). I immediately relaxed and fell into road show mode. Raymie, Steve, Cokey, and I made a strong case for how hiring professional social workers for state social work jobs would ultimately benefit the state of Connecticut. I remember leaving the meeting feeling pretty good.

Raymie: When Steve told me he secured a meeting with the Governor for April 4, I was filled with excitement. My University was exhibiting at the Capitol that same day for a program related to my department and I thought the coincidence was a good sign. It felt like destiny when I received an e–mail from my son's school that he and some other students would be representing the school at the State Capitol on April 4 for Invention Convention Day at the Capitol. It is not often that I have to juggle three co–occurring events at the Capitol, one of them being a meeting with the Governor!

The day itself was full of emotion. I felt like my brain was split, each side working at full power. There was the mom side, making sure that my son had his invention (a device you attach to your shoe that sounds an alarm if you are within tripping distance of an object), was properly dressed in his suit, had his lunch, was in the right place at the right time, etc. Then there was the president of NASW/CT side of the brain, making sure that I had my notes, was properly dressed in a suit, had water and Xanax, was in the right place at the right time, etc.

Luckily our road show team met prior to the meeting with the Governor to prepare. We agreed who would make which points, though in hindsight, I think this would have fallen into place anyway. Who else would have spoken about social work education? We discussed who would open… well, this was a good idea… no dead silence and no jumping all over each other. Lastly, we calmed each other. Or at least they calmed me. This also was a good idea.

The meeting itself went as planned. The before meeting banter was friendly. The Governor remembered Christine and her family, he remembered Steve's father's hardware store also located in the same town, and he said he'd met my son earlier that day. He expressed interest in our issue, and listened carefully as Cokey discussed being a foster parent and a student. Though he made no promises, he was attentive and courteous. I suspect Steve took special pleasure in handing the Governor the open letter, as all the previous campaign efforts appeared to be focused upon gaining signors. This was the culmination of that effort. We left the meeting knowing we had done our best and used our time well.

DCF Commissioner Says "Steve Karp Wins"

Steve: The first big breakthrough, and indeed the biggest success in many ways, was getting DCF to agree to only hire MSWs and BSWs. This proclamation went beyond my request for preference, it was the whole enchilada! Each time we added a new non–social worker organization as a supporter I would email deputy commissioner, Libby Graham, with a subject line such as "good news" and would announce the new supporter and why they signed onto the campaign. At one point I received a reply saying "I appreciate hearing from you again…. I admire your diligence in promoting preferential consideration for BSWs and MSWs…" I think I read that letter more than half a dozen times, searching for a hidden message.

The tipping point came when the DCF commissioner sent a letter to the Appropriations Committee co–chairs asking for suggestions for the legislative session. A clerk told us about the letter and we recommended that the co–chairs write back with only one suggestion: hire MSWs and BSWs. Three weeks later a legislative aide called me to say that going forward DCF was only hiring persons with social work degrees. I was elated! I celebrated with staff and brought home a bottle of wine to continue the celebration.

Once we had DCF on board I wrote to the DSS commissioner and asked that he follow suit. His response was to agree to give preference to candidates with social work degrees. Since then DSS job postings state "MSW degree strongly preferred." It felt great the first time I saw that in writing.

The final step was to get DAS to agree to institutionalize preference into the job specifications impacting all of the state agencies. I was acutely aware that our successes with DCF and DSS were based upon decisions by the respective commissioners. A new commissioner could undo the internal policy decisions of a previous commissioner. If, however, we could get DAS to put preference in place, we would have created a systems change that would be highly unlikely to be reversed.

Raymie: The DCF call from Steve was the first of a series of what I call the "OMG Phone Calls". Steve called to tell me about the DCF success and was clearly happy beyond measure. My response, of course, was a loud “Oh my God!” If the campaign ended here, we were successful. I thought back to the initial board meeting and realized just how far we had come. Interestingly, Steve had never met with the DCF commissioner face to face prior to the decision.

A couple of months after the decision was formalized, Steve and I heard the DCF commissioner speak for a Social Work Month Celebration. Prior to her remarks Steve introduced himself, thus the two finally met, after hearing so much about each other.

Soon after the DCF call came the DSS OMG call, then came some OMG calls around other chapter issues… We were on a roll…

DAS Meetings: The Good, the Bad, the Ugly

Steve: After the initial bursts from the DCF and DSS successes, the campaign hit a DAS roadblock. The only target left was DAS, and my history with DAS on this issue was not positive. DAS had for years refused to budge on the hiring issue, putting up a range of arguments, such as not having enough social workers of color; the unions having to agree; and concerns related to how it may impact on current employees. We answered each of their concerns, in my opinion satisfactorily, and it seemed that we were making progress. After several meetings we were told they would be back in touch “soon.” Apparently my definition of soon is not the same as theirs, as months passed with no response.

To break the silence, I decided to send a letter with signatures from social workers attending our statewide conference calling on DAS to add preference to the social worker job classification. That brought a response, an email on December 23 stating that we had changed our position and were now asking for more, thus DAS had to approach every regional office of each affected agency to determine if preference would cause a problem. I could not believe it and had no idea what position we had changed. I also could not get an answer on December 24! So I spent the next couple of weeks wondering what I had done wrong. Perhaps I had used some terminology incorrectly, leading DAS to decide we had changed our position?

Christine: After DCF and DSS were both on board, DAS continued to stall. I felt we were getting the run around, and I could not figure out why they were hesitating. Were they really that afraid of backlash from the unions? That whole back and forth with Steve leaving voicemail messages that went unanswered was frustrating to observe. I think it was only after Steve raised the campaign with the commissioner’s wife (who was a social worker) when speaking with her about an unrelated issue, that we finally got a call back.

It turned out that Dr. Libby, the State Personnel Manager of Human Resources, was concerned about the legality of adding the word preference. Steve found a social work job description for the Department of Corrections that had the word preference already in the language, showing that precedent had been set.

Steve: During the whole “change of position debacle” I began to fear that I had blown two and a half years of work and was reluctant to share that concern with my chapter leadership. Concern turned to anger, however, and I shared my feelings of dissatisfaction with the state’s Health Care Advocate who simply said go to the Lieutenant Governor, “that’s what I do when I cannot get DAS to act.” I guess you can say the rest is history.

Lt Gov Delivers the Goods

Raymie: When the Malloy administration first took office, the Lieutenant Governor had reached out to the chapter and initiated a meeting with Steve and me in the chapter office. It was an informal opportunity to introduce the Chapter and the work we do. I was glad to have been at that meeting, as it made meeting her a second time, in the more formal setting of her office at the State Capitol less intimidating. Like her boss, the Lieutenant Governor was engaged and charismatic. I was sure we had an “in” when she revealed that her own daughter was a master’s prepared social worker. While Steve explained our successes with DCF and DSS, and our challenge with reaching DAS, I couldn’t help but notice the historical paintings of the revolutionary war that decorated her office walls. It was a grand, stately office with a high cathedral ceiling and rich oak furniture. Steve chatted on about the lack of permanence of our current achievements, while I was thinking, “I could never work in this office, surrounded by scenes of violence and such dark heavy furniture!" It was OK, I had done my part earlier, and Steve was just bringing it home with the "ask". I wrapped up the conversation by asking more about her daughter, and as usual, we left the meeting feeling good. I never told Steve my thoughts about the office. I think he thought I was attentive the whole time.

The Snow Delayed Monday….
The Return to DAS

Steve: Within two weeks of the meeting with the Lieutenant Governor, DAS called asking to meet. Actually, I was never so nervous about a meeting. I was sure they were not calling me to say let's meet to say "no" in–person. That would be an email or letter. Still, I had trouble sleeping the night before. That morning it had snowed and Raymie was unable to make the meeting. I went alone and it was a celebratory moment that I wished Raymie and Chris could have been at with me. DAS agreed to the preference effective immediately. The commissioner came by and I told him that his volume of correspondence would now decrease significantly. He laughed and congratulated me on a job well done.

Raymie: It was the last OMG phone call, though the news was anything but surprising. Steve was uncharacteristically nervous about the meeting, when both the purpose and outcome were so plainly obvious. I felt terrible that I could not be there with him, but the snow had caused a school delay for my son. When Steve called after the meeting to say we had won, there was not enough to say…We had done it! Steve had done the lion's share of the strategy and the leg work, but I knew I had been there for some of it too, contributing wherever I could.

Honoring Our Word

Christine: I left my position as the chapter's political director four days shy of Steve's final meeting at DAS to take a social work teaching position. Once settled at the University, it was important to me, from an integrity standpoint, to make good on the promise we had made to DCF and DSS to "flood their applicant lists with qualified candidates". I therefore organized a workshop at the school on how to apply for state social work jobs for our MSW and BSW candidates. Representatives from DAS' Human Resource department conducted the workshop and reported to me that they would be happy to engage in repeat performances as needed.

Final Reflections

Christine**:** They say luck is the intersection of preparedness and timing, and I think that was at play here. Two events put this campaign near the end zone. The first was when the senate chair of the Appropriations committee, Senator Harp, told Steve that DCF's Commissioner wanted to know what the Senator's priorities were for the Department. Because of the work we had already done with the Appropriation chairs Senator Harp was knowledgeable of our campaign and put it at the top of her list. The other example was meeting Lt. Governor Nancy Wyman and the phone call she made to DAS. That is what finally got DAS to agree to "preference".

In the end, I think it was wise of us not to settle for internal policy decisions at DSS and DCF. As Steve noted, commissioners come and go, and so do their internal policies. It was, therefore, crucial to get preference codified with DAS. For me, that was the most frustrating part of the campaign because that's where we experienced the most resistance. I think it was smart to get the endorsement of non social work groups and other stakeholders, showing it wasn't just social workers caring about social work jobs. Throughout, we stayed true to our ethical principles, always keeping the end user, vulnerable families, central to our discussions.

What resonated with me most, was how we took page after page out of a community organizer's playbook and applied those CO principles and strategies and tactics in every phase of this campaign to achieve our goal. Even though the final touchdown occurred after I left the chapter, I was happy and proud when Steve sent me a copy of the letter from DAS saying that they endorsed preference for social work positions across departments.

Raymie: I will always be proud to have been a part of this Public Access campaign. It is especially meaningful to me, as someone who teaches macro practice, that we used good macro social work practice theory, skills and knowledge to increase access to clinical social work services. For me, this is a perfect example of how and why we are one profession requiring the range of skills and tools that make up social work. Ultimately the goal was to help more people benefit from clinical social work services. However, true to our values, our efforts were focused on serving some of the more vulnerable residents of our state.

Personally, my affiliation with NASW/CT has been long and meaningful and to know that this change, among others, occurred during my presidency is an honor. I only did what any reasonable president would do. I trusted the talents and wisdom of my esteemed executive director colleague, supporting him as needed. I did my best to be as accessible and present as possible, without putting my own job or family at risk. I saw my role as supporter, confidant, critic, friend, colleague and humorist.

I believe that Connecticut is a better place because of the work that we did. I believe that as the workforce professionalizes, continuity of care for some of Connecticut's most vulnerable residents will improve. I believe that social workers will also benefit, both because their degree will be recognized and because the public will be seeing real social workers performing in social work roles. This will help our public image. I look forward to the days to come.

Steve: Prior to this campaign if you had asked me what I was most proud of in my time with NASW/CT I would have said passage of the social work confidentiality statute. But this campaign exceeded that accomplishment by giving individuals and families served by public sector social service agencies the same qualified professionals as clients in the private sector. I am most proud of that fact.

The campaign challenged me to think strategically on multiple levels. I used every skill set I have learned as a macro social work practitioner and community organizer. I never doubted that we were on the right track, but there sure were sleepless nights throughout the process. I felt the high of "winning" with DCF and the disappointment of having organizations that I greatly respected decline to support us.

I am indebted to the chapter's leadership for allowing me to take on this campaign and for supporting our work. To the best of my knowledge we are one of only half a dozen states that are hiring qualified BSWs and MSWs for child welfare social work. Of those states we are the first one to accomplish this by persuading the executive branch, rather than using licensing statutes or other statutory language. It still gives me a thrill every time I think about it.

For nearly 25 years I sought to have equality in the competence of public sector social workers with those in the private sector. I kept my eye on the prize, some years working toward this goal, when an opportunity seemed to present itself, and other years busying myself with other important projects. In conclusion, I can only say I am one persistent little bugger!

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What Caregivers have Taught Me: Reflections from an Adult Day Care Setting

Carol Weissmann Mauck

Abstract: According to the National Study of Long Care Providers, there are 4,800 adult day centers nationwide (Centers for Disease Control and National Center for Health Statistics, National Study of Long Term Care Providers, 2012). I had the privilege of being a founder and owner of one of these centers for 17 years. This narrative reflection focuses on my professional experiences with caregivers' decision-making journey in adult day services. As I reflect back on the process, I was on my own quest to solve a problem I had identified while working in long–term care. I queried how to deliver supervised care to older adults without it feeling like congregate care. In another town, there was an adult day center which was located in a single family home. After seeing this center, I realized I had found the answer and subsequently started a center in a caregiver palatable house. I did not realize at the time that the customers and caregivers were a packaged deal. The reflections I offer are based on my professional understanding and growth through direct practice experience with caregivers, and what I have learned from caregivers about their decision-making process in adult day services.

Keywords: relationships, aging

Reflections on Care Giving Decision-Making

There are approximately 270,000 participants in adult day services who have many different reasons for needing out-of-home care (Harris-Kojetin, et al, 2013). Admissions to centers serve a variety of customers including those who need respite care, therapy, nursing services, and physical and/or mental stimulation. (Illinois Department on Aging, August, 2015). The mainstay of adult day center care is that customers are able to remain in their homes, or the homes of a loved one, while receiving care at the center during the day time (Gitlin, et al, 2006). The center I owned had a customer population based on the admission criteria of adults 18 years or older. The population included adults with closed head injuries, developmental disabilities, seniors with Alzheimer's disease or related dementias, or individuals in stages of recovery from acute illness.

Reasons for admission to the center were as varied as the attendance schedules of the customers. From my experience as a center owner, I have learned the complexities of caregiving. Caregiving is a generic term used to describe how anyone, from the mailman or the grocery store clerk, simply looks out for another person, and may provide some physical assistance. In literature, they are often divided into two categories, paid (formal) and unpaid (informal) caregivers, who do different parts of activities of daily living. Roth and colleagues (2015) discuss these definitions and look at caregiving in a refreshingly new way by posing the idea that caregiving isn't always a burden. Caregivers come in all different shapes, sizes, ages, and represent many different family groups. (American Association for Retired Persons and National Alliance for Caregiving Report, 2015). Most commonly, the caregivers in adult day services were spouses, significant others, children, grandchildren, siblings, and on occasion, hired professional or private caregivers. Not all of these caregivers considered the process a burden. Some would verbalize to me that it was a privilege to care for a loved one. Attitudes about care giving can change from generation to generation, based upon the history of relationships, cultural heritage influences, and belief systems (Sun, et al, 2012).

While gaining experience working with caregiving families and support groups, I discovered that caregivers either wanted to be responsible for decisions, or that they were not used to making decisions. Many seemed to have difficulty realizing and deciding when it was time to place their loved one in an out-of-home setting.

Culturally Diverse Caregiving

Different cultures often take care of their care recipients according to the beliefs and values of their cultural heritage (Dilworth-Anderson, Gibson, 2002).

However, if the caregiver has become Americanized, there is a possibility that there may be conflicting generational beliefs (Sun, 2012). I have observed that it is especially challenging for care recipients with dementia who are from a different culture and who speak English as a second language. I experienced this first hand with several customers who were born in other countries and moved here to live with relatives. It was a difficult adjustment for these customers to be introduced to a new culture at this stage in their lives, especially those with dementia. It seemed to decrease their ability to tolerate the communication difficulties surrounding their care needs. The customers would call out in their native language, and often became agitated when direct care was given. Some individuals with dementia may not be able to adjust to an adult day center care, unless they participate in a culturally relevant center. In larger cities this can be an option. In Chicago, for example, there are adult day centers that offer care to culturally diverse populations such as Russian, Chinese, Korean, Vietnamese and Hispanic (Illinois Department on Aging, 2007). An organization, the Coalition of Limited English Speaking Elderly, has member agencies that address some of these concerns in their resource of language lists for older adults. Customers may be at risk, as their dementia progresses, to revert back to their language of origin (Alzheimer's Association, 2014). The most difficult decision faced by caregivers was their original decision, if or when to start out-of-home care.

Initial Decision-Making Observation

Often at my center, the decision to enroll would be deferred to the client who had the memory loss. When caregivers left the decision to attend adult day care to the care recipient, they often chose not to attend. Through the experience of working in direct practice with caregivers, I was able to observe the difficulty a caregiver had in making that initial decision to use out-of–home care. When faced with a caregiver who is having decision difficulty, I had success with breaking down the process into eight steps, taking one step at a time (see Figure 1 below).

Figure 1: Decision to Place in ADS: The Eight Step Process

Making the Decision: An the Eight Step Plan

The plan begins with the identification of decision-makers, legal and emotional, who should be included in the process. A family member of a potential client taught me this lesson by informing me one day, after meeting with her for several weeks, by saying ,"I think I should talk to my sisters about taking mom to the center." All the decision-makers should be identified before the process begins. Decision-makers should create a list of what they see as the pros and cons of adult day services for their loved one. After the lists are complete, it is the professional's responsibility to take each item and conduct a group review. Discussion points should include a new interpretation of services, such as considering adult day services as a treatment approach to memory loss or other physical and mental issues. Another focus point should be benefits caregivers may never have considered. Example focal points may be easy access to medical questions, therapy services, or transportation to doctor's appointments. The best results from these discussions were achieved when all decision-makers had input at the same time. In some instances, this may require evening home visits. The extra time is an investment in rapport development and creates a non-intimidating and friendlier environment for discussion.

I like to think that adult day services invented the offer of a flexible schedule in health care. Centers can be open up to six days a week (some seven) and have hours that accommodate caregivers' work schedules; they can also bill by the hour, day, week or month, and often offer sliding fee scales (Met Life, 2010). Services may vary according to the type of center (NSLTCP, 2012). This schedule flexibility appeals to caregivers because it offers the ability to gradually introduce the center to the care recipient. Routine schedules of at least two days a week should be established in consideration to both groups (Savard, Leduc, Lebel, Beland, & Bergman, 2009). This will help the caregiver plan stress-relieving activities, and the care recipient–especially with those with memory loss–to find comfort in a routine (Zarit, et al, 2014).

I recommend the pre-paid trial time period to encourage caregivers to commit to their decision of adult day services instead of a more intimidating contract. As you utilize this plan, there may be a point at which you could include the care recipient in the process. The decision as to when and how to include the care recipient should be determined by the degree and type of impairment.

Once a decision is made to use adult day services and the pre-paid trial schedule is confirmed, transitioning into accepting the center's population is the next hurdle for the caregiver and care recipient. This part of the process is similar to applying the theory of teenager's tough love as a persuasion technique. This approach from a caregiver's perspective is evaluating their motivation to be a caregiver and keep their loved one out of more confined care. Additionally, they must remain healthy, both physically and mentally, to deliver care (Schulz & Sherwood, 2008). This means they must get enough rest, maintain healthy eating habits, exercise, and take time for themselves. The need for caregiver wellness is often stressed by researchers (Pallor, et al, 2014). Without a wellness commitment, their loved one may need to be moved into more confined congregate care. This is not the outcome families are looking for in adult day care (Zarit, et al, 2011). In actuality, the tough love approach is an avenue that caregivers relate to and appreciate. I recall a situation in which this technique assisted a working daughter in getting her mother to accept adult day care as the better choice. The daughter embraced the tough-love approach and successfully utilized the concept by convincing her mother to attend starting out on a part-time basis and turning into full–time. Another approach for the refusal process which a caregiver taught me was pointing out to her mother that she, as caregiver, also had to work to support her family, but still wanted to care for her mother. There was only one choice for the caregiver, to work as the sole bread winner. She gave her mother two choices: adult day care or confined congregate care. This may sound assertive, but was motivated by necessity.

The issue of timing is also important in the caregiver's decision-making plan in adult day care. Caregivers seek out-of-home care when they have reached their limit of ability to continue care. Reasons for this are multi-dimensional, such as fear of last resort choices, financial pressures, or looking like a failure. Caregivers shared with me that they realized, after seeing the benefits of respite care at adult day services, they should have made the decision months earlier, but were afraid to trust a loved one's care to others. Grateful caregivers' comments would include testimonials, such as, "You saved my life," or "For the first time in months, I slept all night." The implication of these heartfelt comments is that it gave them their freedom and autonomy back while helping them to realize what they had given up to be a caregiver. On rare occasions, families would make a decision to move to confined congregate care after this realization.

Building Decision-Making Rapport with Caregivers and Customers

It is hard to turn daily care of a loved one over to a stranger, even though we are identified as experts. Perhaps the reason for this could be a symptom of guilt or stressors in the care relationship (Austrom, et al, 2014). Verbal reassurances cannot convince some caregivers that their mother had a wonderful time while she was at the center, and was laughing, smiling and talking throughout the day. Many times a care recipient was picked up by their caregiver and asked, "What did you do today Mom?" A usual reply: "Nothing, just sat. I was bored." This response, though inaccurate, was often believed by families. Technology, in the form of videos and mobile apps, offer adult day care centers the ability to demonstrate the engagement of the care recipient in the program to the caregivers with the added benefit of reassurance. Similar to what is used in child day care, parents/caregivers are reassured that the child/adult is safe and engaged in activities by a mobile app with a video (Tjarder, A. 2012).

Expectations were high by caregivers that the care recipient would love the center immediately, and begin to socialize with peers. Often this was not the case because an adjustment period is needed. If a family made it through the adjustment period, then chances were they would begin to see changes in their loved one. Small changes observed were more smiles, sleeping better, improved appetite, and even increases in cognitive abilities from physical and mental stimulation at the center. These changes take time, but they can happen. An example of establishing a rapport with a dementia customer occurred one day when I was in a local building supply store. I recognized one of my customers wandering around the store appearing lost. Following a short distance away, I spotted her husband as she came running up to me laughing and smiling with arms outstretched. She threw her arms around me and gave me a very big smile while hugging me and attempting to verbalize, "You're…yes… are…you….I." She could not remember my name nor engage in a conversation, but recognized me as someone who cared for her in a special way. We had established a rapport through an adult day center, as caregiver and care recipient.

To illustrate how important adult day centers can become to care recipients, I will share this story of an individual who had moderate dementia and attended the center several times a week. The caregiver was a long time spouse. One scorching summer day, on a day the customer was not scheduled, he showed up at the door of the center with a stranger who asked if the customer belonged at the center. Once confirmed by staff, the stranger proceeded to share the story that the customer was found walking alone in the street in the hot sun appearing to be lost. The stranger stopped the car and asked if he was alright. The customer was able to communicate enough information that the driver understood he was looking for someplace or someone. Worried that he was becoming overheated, the stranger decided to offer him a ride to my adult day center located several miles down the road and ask if he belonged there. Though the customer was suffering from dementia, he had left his house, walked over several miles to find the place that felt like home and where there were friends. These strong bonds can develop between center staff and customers given time to grow. Some individuals remain in care at centers for years at a time; as a provider, the longest stay I experienced was eleven years.

Caregiving Decision-Making Via Support Groups

According to the Met Life Survey, 58% of the adult day services include monthly caregiver support groups. The groups often run the gamut of emotions and can include tears and laughter in the same meeting. Caregivers share their stories, their worst days and best days. I have heard caregivers admit to feeling irritable toward their care recipients. Many times they described feeling frustrated when they were asked repetitive questions. Some responded by saying, "Don't you remember? I told you what time this morning," followed by feelings of guilt and remorse. Being able to share common experiences in a support group, offers caregivers opportunities to speak about frustrations, anger and fears of caregiving (Alzheimer's Association Support Groups, 2015).

Support groups offer a safe and secure place for caregivers to express their inner–most feelings in a supportive, "we have all been there" environment. In my center, caregivers often expressed a deep–seeded frustration with memory loss. A caregiver expressed this very emotion in a meeting once, by explaining how they were finally able to overcome this feeling by a realization that they had to change. The care recipient is unable to change, and as the disease process continues, the caregiver must become adaptable. It becomes a matter of reframing the caregiver's thought process and not that of the care recipient (Paller, et al, 2014). The revelation that your parent or spouse is no longer able to be in control, and by default, you are in control, is a big step in getting rid of the anger and frustration. Once this caregiver was able to put what needed to be done into words, the other caregivers agreed and provided support. If caregivers are annoyed by irritating behaviors, they are the ones who must reframe how they respond.

In support group, caregivers would often share helpful care tips. One creative tip was shared by a spouse caregiver trying to maintain her sense of humor. With some embarrassment, she shared her care tip for responding to repeated requests for daily aspirin from her spouse. Despite the fact that the doctor did not recommend daily aspirin, her spouse was fixated on it. She came up with her own innovative solution. She put white breath mints in an aspirin bottle and gave him his "daily" aspirin. The physician approved of this intervention which preserved the dignity of the care recipient.

In a supportive environment, it is helpful to have caregivers identify their caregiver deal–breakers. Borrowing from a business term, I would ask them in the support group what it would take for them to place their care recipient in more confined care. Answers varied, depending on the type of relationship with the care recipient. Frequent responses from the caregivers included physical aggression, incontinence or not recognizing the caregiver. By acknowledging their deal–breakers in advance, caregivers were more prepared for making the decision to move their loved one into the next level of care.

Anticipatory Transitional Decision-Making

Changing levels of care is never an easy process for the caregivers or the care recipients. Caregivers often don't want to acknowledge that the level of care required has changed because they are afraid of what the future will be. This transition is difficult for everyone concerned. The care plan process is often the perfect venue to discuss any observed changes and possible outcomes. The Met Life survey has noted that 96% of adult day centers use care plans as a tool to assess changes in the customers, and to update treatment, functional status, and medication information (Met Life Survey, 2010). Using a gradual approach is the best method to assist caregivers through the transition process. Often caregivers have said to me, "You have to be the one to tell me when mom is too much to care for." These are difficult conversations, but safety issues provide assessment tools for caregivers and professionals to use when deciding if or when to transition to confined care. I found that caregivers appreciated openness and frankness in transition discussions, and it is what I have labeled "anticipatory transitional decision-making." Everyone is a beneficiary if the process is the "anticipatory transitional" method of taking gradual steps, and having open and frank discussions along the caregiving journey.

Caregivers have taught me that caregiving is meant to be a generic term. Caregivers are not always bound by a formal relationship to the care recipient, but can be bound by simply the process of caring for another person (Zarit, 2011). However, it can also be a form of duty. At times, siblings compete to have the responsibility to control the care of their loved one. The responsibility may shift from one caregiver to another as caregivers need a break. In my experience, it was not uncommon for customers to be rotated by family members and attend one month at a time during the rotation. Caregivers would do better and be able to care longer for their care recipient while they were in an adult day care when the responsibilities were shared with others.

Though I was the professional, the customers and their caregivers in adult day services were excellent educators. In my adult day center, I could not decide who was the customer, the family or the care recipient. Assuming the role of a caregiver as an adult day services provider taught me that caregivers are very much a package deal. There are some people who come by it naturally, and those who try harder to succeed. During a support group, a spouse offered an insightful response, "People ask me, now that my wife is gone, would I do it again knowing how hard it was? I really had to think about it, but in the long run, I would. I may do some things differently, but I would do it." Reflecting on my caregiver experiences as a provider of adult day services, I agree, I would do it again. I may do things differently, because experienced caregivers are knowledgeable educators.

Recommendations for Future Research and Practice

As I reviewed the literature for this reflective article, I discovered that there are gaps in literature for adult day services. Though this service has been around in its earliest form since 1940 (National Adult Day Services Association, 2015), there is little information about how important it is in assisting families with loved ones to age in place. Another aspect which seems to be overlooked is the inherent cost effectiveness of adult day services in a nation of increasing and complicated health care costs. Since I have sold my business, I am able to look at adult day services in a more insightful and objective manner, which leads me to suggest that there are multiple areas of potential research, and opportunities for data collection in this industry. There are several quantitative surveys such as The Met Life National Study on Adult Day Services, Glenworth 2015 Cost of Care Survey, and the survey from the National Study of Long Term Care Providers.

These surveys provide statistical information, but there needs to be more exploration into qualitative studies on such topics as adult day service's role in assisting older adults to age in place, customer's adjustment to adult day care, and social engagement activities. In addition, there are multiple models of adult day services and it would be advantageous to have data about which models provide care most successfully for specific populations. I will acknowledge first–hand, that while data collection could be a challenge, providers would welcome partnering with researchers in an effort to educate the caregiving public about the wide range of therapeutic and multi-dimensional services.

As a practitioner in this industry, I found adult day center program directors to be seriously committed to providing services to their customers and families. Nevertheless, I was able to identify specific issues which may need to be addressed by the industry in the future. 39% of ADS centers are free standing, however, a majority are part of a parent company (Met Life Survey, 2010). The parent companies are from a wide variety of private, governmental, religious, and health care affiliations. This creates layers of administration between the adult center program directors and their fiscal administrators; layers that can encumber the direct delivery of services to the customer and families. While this wide variety of affiliations enhances the multi-levels of service flexibilities, it also creates frustrations and impediments to direct program delivery. As the national need for aging services increases, this market pressure may afford researchers and providers the opportunities to come together in a mutual national service plan that focuses on adult day services.

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The Harvest is the Best Teacher: A Narrative on Food Insecurity and Community Gardening with Children and Adolescents

Gayle Mallinger and Molly Kerby

Abstract: As the national climate and attitudes toward local organic food progressed in the United States, farmers markets, school and community gardens, and campaigns to increase vegetable consumption among children and adolescents skyrocketed. Unfortunately, many communities are beginning to realize disparities exist in poverty-stricken neighborhoods in term of access to fresh produce, education, and food programs This narrative follows a community garden project over three years at the Boys & Girls Club in a semi-rural city in Kentucky. Participants prepared the garden site, planted seeds, and harvested vegetables as part of a Junior Master Gardener program in the afterschool and summer programs.

Keywords: community; youth education; child welfare; health

Discovering Fertile Ground

In March 2009, headlines across the United States exploded with groundbreaking news that first lady, Michelle Obama, would be planting a kitchen garden at the White House. Washington Post staff writer, Jane Black, enthusiastically reported the "1,100-square-foot garden will include 55 kinds of vegetables, including peppers, spinach and, yes, arugula" (Black, 2009). Though this would not be the first time in history Capitol Hill housed a garden (i.e, the "victory gardens" established in the 1940s), Americans rallied behind the first family's commitment to growing wholesome organic food, supporting farmers, and tackling food disparities and childhood obesity in the United States. While farmers market had sprouted in masses across the country and public health officials had been sounding alarms about the hazards of the American diet for the decades, the White House garden became a precipitating factor in fueling a new food revolution.

Meanwhile, in the small semi-rural city of Bowling Green, Kentucky (KY), community gardens and markets began to gain momentum and permeate the community. Over a three year period, the two well-established local farmers market were joined by three competitive markets, including a city and county owned/operated outdoor local foods pavilion. The stage was set at the national level, trickled through the states, and manifested in our backyards. Newly sprouted non-profit organizations and local restaurants aimed their forces at creating sustainable community foods systems and grant funding for food-related projects became readily available. It seemed everyone had combined forces to join the food revolution in Bowling Green, KY. Or, was this an idealist vision formed from a place of privilege? While on the surface the momentum was fierce, a careful glance at the customers at the Saturday morning markets revealed an extremely homogenous group of white, middle to upper-middle class patrons. Had we all missed the absence of people of color? Had anyone considered transportation issues or reaching out to those on public assistance? What about the community members on the "other side of the tracks?" And, most importantly, what about the children in those communities?

In light of this painfully obvious disparity, a shift in lens of privilege must occur so we can move from idealistic representations of harmonious social conditions and critically analyze social problems and stigma affecting communities of poverty. The inability to understand power and privilege often precludes the ability to accurately measure the success of community projects and programs designed to alleviate or solve a public problem. Though social dissonance is a constant factor of human life, the political and economic framework of the latter part of the twentieth century was built upon the argument that social change and equity are central facets of sustainability and resilience. This approach remains key in understanding the context of food security and justice in our communities.

Breaking New Ground

On a cold, blustery day, four faculty members from various colleges at Western Kentucky University (WKU), convened at the campus bagel shop to discuss a joint response to a newly announced funding opportunity designed to promote innovative intercollegiate collaboration. Although our fields of study were diverse, we shared a common interest sustainable gardening practices and were involved in the local community food movement. Molly, a professor from Diversity and Community Studies, gathered the group of faculty from Education (Jeanine) and Agriculture (Martin) and Social Work (Gayle). Armed with our respective lattes and herbal teas, we tossed around ideas that centered on our intersecting passion for sustainable gardens and social justice.

After a brief discussion, we decided to propose a sustainable community gardening project in the northern part of the city at the Boys & Girls Club with participants in the afterschool program. The Boys & Girl Club sits adjacent to a local elementary school (Parker Bennett) ranked in the 10th percentile in our state and classified as "needs improvement" by the state's Department of Education. The majority of the children attending the elementary school participate in the afterschool program because of its close proximity. The elementary school and the Boys & Girls Club are separated by a patch of grass that has been converted to a small soccer field with a walking track outlining the perimeter. The surrounding neighborhood, now part of the Housing Authority, was once home to a thriving economy of local groceries, bakeries, "five and dimes," gas stations, and hardware stores. Over the past few decades, the "mom and pop" stores have been forced out of business by "big box" conglomerates and chain grocery stores. The collapse of the economy coupled with "white flight" and gentrification have contributed to the poverty rate, isolation, and food desert in the neighborhood. In addition, Bowling Green, Kentucky has experienced an increase in the number of low-income and refugee families over the past two decades. The Housing Authority of Bowling Green provides residence to 1463 individuals; almost half reside in female headed homes and nearly half of the residents are African American. In addition, 31.6% of those living in Bowling Green's subsidized housing are refugees.

The racial composition of the elementary school is 35.90% African American, 4.66 % Asian/Pacific Islander, 36.60 % Hispanic, and 22.84 % White. More than 50% of the students at the elementary school speak English as a second language. African American male students' kindergarten preparation scores are 17.5 compared to their white male counterparts' scores of 51.6. Students at this school test at 21.67 % proficiency in science compared to the state average of 70.53 %; math and reading proficiency rates for students is also significantly lower than the state average .In the aggregate, the school ranked 651st out of 718 elementary schools in the state. The school has been eligible for the Community Eligibility Option (a universal free school breakfast and lunch service throughout the calendar year) for students in high-poverty areas since 2012 (Kentucky Department of Education, 2015).

In the last few years, school gardening projects have sprouted across the country. School gardens influence improved eating behaviors in children, specifically, increased fruit and vegetable consumption (Castro, Samuels, & Harman, 2013; Christian, Evans, Conner, & Cadel, 2012; Hazzard, Moreno, Beall, & Zidenberg-Cherr, 2012). In addition, school gardening, in concert with a supporting curriculum, has also been credited with deepening students' mastery of science, math, and language arts, as well as enhancing their understanding of the environment (Beckrich, 2011; Graham, Beall, Lussier, McLaughlin, & Zidenberg-Cherr, 2005; Johnson, 2012; Lyon, & Bragg, 2011). The experiential learning that gardening provides also emphasizes problem-solving and critical thinking skills (Graham, et al., 2011). In addition to positive effects on students and teachers, school gardens provide numerous opportunities for parental involvement. Parents whose work schedules prohibit volunteerism during regular school hours can tend gardens after school or on weekends. The value of parental involvement in the education of children is well documented and indicates that parental involvement is tied to enhanced achievement, regardless of race/ethnicity, social class, or parents' educational level (see, for example, Altschul, 2011; Kim, 2000; LaRocque, Kleiman, & Darling, 2011). Engagement of immigrant families, however, is especially challenging. In addition to limited English skills, these families experience cultural differences that limit their confidence, and therefore interaction, with their children's school systems (Carreon, Drake, & Barton, 2005; Md-Yunus, 2008). Barriers to parental involvement include language, literacy, and work schedules (Gutman & Eccles, 1999). Many children from immigrant parents or children of color are at an increased risk for poverty, lack of educational success, and minority stress. All of these factors lead to lower academic performance, compared to those of Caucasian, native born decent (Burchinal, Roberts, Zeisel, Hennon, & Hooper, 2006). It is extremely important for parents to be involved in their children's lives, especially those of immigrant descent. Parental school involvement is one factor that buffers the relationship between poverty and school achievement (Brody & Flor, 1998).Gardening is a universal language; thus, school gardens provide a venue for parents with limited English skills and limited formal schooling (Ozer, 2007).

The gardening project was designed to teach participants to plant heirloom vegetables and herbs that can be grown in the fall/spring school sessions with the intention of "seed-saving" to eventually create a community seed bank. Afterschool program participants would have increased opportunity to practice math and science skills through learning to plant, measure and document growth. This project would also increase opportunities for parental involvement, especially among refugee families with limited English skills. In addition, we hoped the project, shared by the four colleges, would allow a broad range of multidisciplinary student involvement. When colleges and universities provide a structure for students to contribute to the overall quality of the institution and bridge community, a sense of empowerment develops among faculty, students, and community stakeholders. As we envisioned it, the sustainable garden would also provide opportunities for parental involvement, consistent with the school's Comprehensive Improvement Plan.

We approached the principal of the elementary school and the executive director of the Boys and Girls Club with the idea for the garden. They wisely suggested that we meet with several teachers, workers at the afterschool program, representatives from the Housing Authority, and parents. Gayle, Molly, and Janine facilitated this focus group held in the school's library. Unfortunately, none of the parents came to the meeting. Seated in children's chairs around a short rectangular table, the teachers, program worker, and Housing Authority representative provided key information from their unique perspectives about the community, including its strengths and areas of concern. Lack of parental participation was cited as the most pressing problem. Specifically, the principal shared that she was unable to convince any of the families to lead or even attend the Parent Teacher Organization. The teachers, principal, and representatives from the Boys and Girls Club and Housing Authority stated that they were hopeful that the proposed garden would promote parental involvement and community cohesion.

After the meeting, Molly, Gayle and Janine met over salads and tea and discussed the next steps to put the plan to fruition. Martin had already shared his interest in learning how seeds from the homelands of refugee families would grow in our area. In addition, he promised he and his group of students would be responsible for the "grunt work." Janine was most interested in providing opportunities for her students to develop curricula for the gardening project. She offered to develop a Junior Master Gardener certificate. This would allow the afterschool program participants the opportunity to engage in experiences that promote an appreciation for the environment and an understanding of sustainable gardening practices. Gayle and Molly had a shared interest in the interconnectedness among social-cultural, economic, and environmental issues and their combined impact on the lives of children in this community. Specifically, both were concerned with risk and protection and wanted to evaluate the efficacy of the garden project on building resilience.

In summer 2014, on a hot and humid day early in

June, Martin, Molly, and Janine rounded up a crew of college students, community members, and neighborhood children to break ground for the garden (Figure 1.). The spring months had been particularly rainy that year, so we were a month or so behind our intended schedule; we had to work fast. We began work at nine o'clock that Friday morning. Like a well-oiled machine, the children laid paper from a giant roll donated by the local newspaper. As the paper was laid, college student volunteers shoveled the mounds of dirt delivered by a borrow back-hoe over the area. By noon that day, the garden was ready for planting by students in Janine's Junior Master Gardener class.

Sowing the Seeds

With the garden space prepared, children in the summer Junior Master Gardener program at the Boys & Girls Club began sowing seeds. They planted a variety of seasonal vegetables including squash, tomatoes, corn, lima beans, okra, watermelon, and a whole host of southern favorites. Volunteers and interns from WKU dropped by occasionally to help them with small projects for the garden as well. For example, one field student from the Department of Social Work led the children in making popsicle-stick garden markers and an automatic watering system using three-liter plastic soda bottles turned upside down. Students from the Department of Education began working with the participants on worm farming and composting in a small area next to the garden. Through each step, the children were taught basic information about photosynthesis, plant ecology, biological systems, and ecosystems.

Figure 1: The ground-breaking crew, June 2014.

During Kentucky's hot, dry summer months (June, July, and August), groups from around the community helped keep the garden weeded and watered. One of the most rewarding relationships built from this project was with the Kelly Autism Program (KAP). The KAP provides services to individuals age seven through young adulthood who have been diagnosed on the autism spectrum continuum. Two days a week, KAP summer participants spent the morning working with the Boys & Girls Club gardeners pulling weeds, watering, and learning about everything from plant identification to best practices in growing. The experience not only helped KAP participants learn to function in a social environment but provide the Boys & Girls club summer program children with an opportunity to work with others different from themselves. The summer progressed and the garden flourished. Vegetables were harvested weekly and placed in a box in the office for parents to take home when they picked up their children. One of the staff members at the Boys & Girls Club, Ellie, taught the children to make zucchini bread and other dishes from various vegetables in the garden. While the growing season in Kentucky is relatively short, crops are prolific in the summer months. Around the end of August, just as local schools start their academic year, production slows and plants begin to die out. This natural phenomenon sets the stage for the afterschool program in terms of harvesting, seed saving, and cold weather composting education.

The Harvest

As the temperature grew colder in southcentral Kentucky, final harvest time arrived. In conjunction with the afterschool program, the faculty and university students planned a celebration dinner using the yield from the garden. Our well-intended plan was to invite the families of the children who participated in the project and facilitate arts and crafts activities. Using the remaining funds from our internal grant, we purchased stepping stones, clay pots, and weatherproof paints. Several vendors from one of the local farmers markets contributed heirloom seeds for the children to plant in the uniquely decorated pots. Another vendor donated pickled okra, asparagus, and green beans to supplement our garden bounty). Kentuckians, like many southerners, enjoy their fresh vegetables dipped in cold and creamy ranch dressing. Molly, whipped together a luxurious dip to entice the children to taste the vegetables that they grew. Since we advertised the festivity as "dinner,' we decided at the last minute to add pizza from a shop that uses only local, organic ingredients and Gayle baked desserts.

The executive director of the Boys and Girls Club suggested we hold the dinner from 4 to 6 p.m., since this was the time that most of the parents and guardians picked up the children. We had a fairly good response. Approximately ten adults and a host of siblings joined their gardeners for the celebration. We intended to start the evening with painting individualized stepping stones to be used as a perimeter for the garden. Unfortunately, Mother Nature had a different idea. The fall rain had been heavy and persistent and the stepping stones had been stored outside. The weather-proof paint would not adhere to the soaked stone.

Always a flexible bunch, we went to Plan B. We gave each child and family member a small clay pot to decorate. All seemed to enjoy the activity, as evidenced by lively interaction between families and laughter.

Following the arts activity, the dinner showcasing the garden's herbs and vegetables commenced. The faculty were surprised, mystified, and a tad horrified to hear a mother scolding her child as she reached for a ripe cherry tomato. As she pushed the fruit out of her child's hand, she exclaimed, "Don't eat that; it's nasty!" Although the loudest, she was not the only parent who discouraged a child from eating the produce from the garden. The pizzas, cookies, and lemon bars disappeared; all that remained was a beautiful vegetable platter and a container of barely touched ranch dip. We were disheartened but the executive director had a brilliant idea and initiated a competitive game to tempt the children to try the vegetables. She certainly knew her audience! After swaddling the various vegetables in dressing, the club members and their siblings ate a variety of the produce they grew.

Continued Growth

In spring 2015, Molly and Gayle received a grant from the Kentucky Governor's Commonwealth Garden Initiative to revitalize, expand, and enhance the community garden at the Bowling Green Housing

Authority. The purpose of the grant initiative is to encourage healthy eating and increase access to locally grown foods in Kentucky communities. The project will receive assistance for one year including seed/transplants and one consultation on the planning and implementation of best practices in local gardening and production of food. The garden will also be used for community education and demonstration in conjunction with a similar project at the Boys & Girls club funded by a WKU IRCAP grant during 2014-15. In spring of 2015, both garden projects were infused into the curriculum of a public problem solving class.

Diversity and Community Studies (Public Problem-solving), a core course in the Diversity & Community Studies major, investigates the development of collective power, capacities, and responsibilities using community-based research (CBR). The collaborative approach of CBR equitably involves all partners in the research process, recognizes the unique strengths that each brings, and integrates theory with practice. Students worked in groups at the Housing Authority, the Boys & Girls Club, WKU Food Pantry, and WKU Project Grow to build a relationship between the community and the university. All of the projects focused on the economic, sociocultural, and environmental aspects of food insecurity in the United States. The students spent the last part of the semester in "the field" working side by side with their community partners in an effort to formulate solutions to real-life problems, identify key stakeholders, and create asset maps.

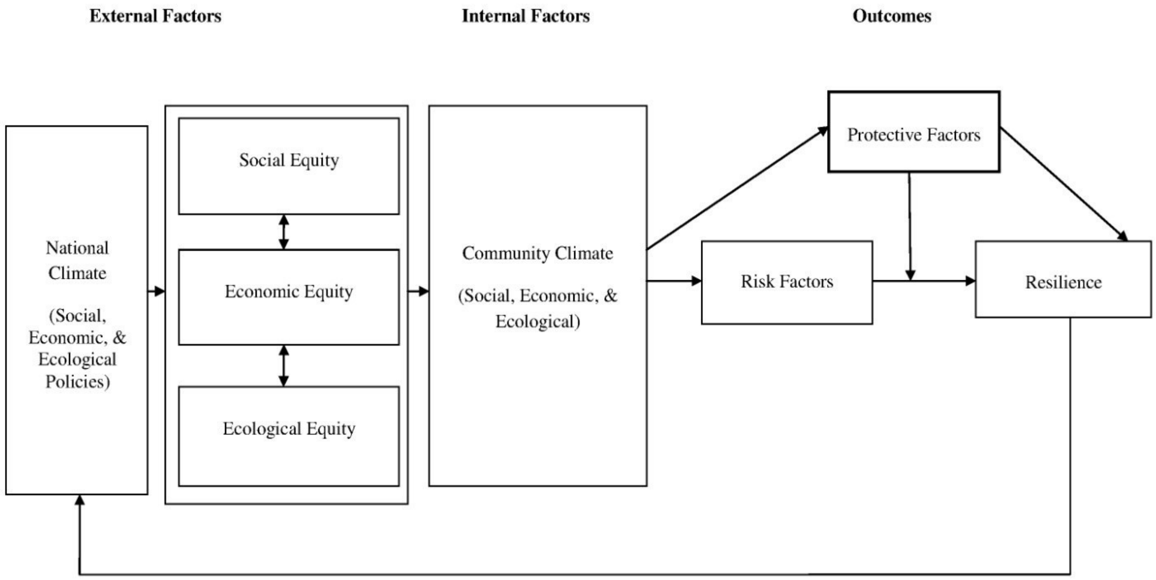
As part of their final, the four groups of students competed for a fictitious $5,000 grant using data collected from the communities and applying the principles of community-based research. As one student said in reflection, "this is the first class I have had that actually let us apply what we learned to the outside world. I not only learned about community-based research but how people struggle in communities, how to communicate with people who don't speak English, and even how to plant vegetables. Up until this point in my life, I had never seen a strawberry plant or squash seeds or anything like that. But I think the best part was working with the community to solve problems together. I learned that the real experts are the people who live the problem. It was a great learning experience!"

Similarly, Gayle had several Social Work majors work on the project as part of their Directed Independent Study course. The students were particularly focused on food justice as an extension of social, economic, and environmental justice. Food justice examines the influences of race, class, and gender on the production and consumption of food (Alkon, 2014). In principle and strategy, remediating structural inequalities related to food distribution helps build coalitions with communities at risk (Gottleib & Joshi, 2010). The students were passionate about Bowling Green's marginalized communities having the right to grow and consume healthy, affordable, and culturally appropriate food. They rolled up their sleeves, helped plant, weed, and water. They met with children who were part of the afterschool gardening and discussed nutritional choices, and assisted with arts and crafts activities, including painting stepping stones to border the garden. In their reflective journals, the students reported that they learned a lot about lack of access to healthy fresh foods and its impact on the children's food choices. One student said that "the social work department should require students in the community and organization practice course to work at the Boys and Girls Club so that they can really understand how this organization helps kids in this neighborhood." Another student wrote, "This Independent Study changed the course of my life! I started the program sure that I was going to be a therapist and now I want to do community organizing. This really helped me see the relationship between micro, mezzo, and macro practice." This particular student is now working on the extension of this project, the community garden at the Housing Authority. She is in the beginning stages of a research project looking at the impact of the garden on food insecurity.

The "Forest for the Trees" Problem: Reflections

The garden project, now in its third year, was conceptualized using a new model of sustainability (Kerby & Mallinger, 2014) (Figure 2). The model begins with an understanding of national climate (social, economic, and ecological polices) and how it effects the internal factors and outcomes of community resilience. In this narrative, the first lady's garden project at the White House sets the tone for the national climate by creating an atmosphere conducive to organic gardening, local food, and prevention of childhood obesity. This positive national context paved the way for us to begin conversations in the northern part of our city about healthy eating and education.

Figure 2: A New Conceptual Model of Sustainability



Following the arrow (to the right) from national climate, factors of equity in this model directly impact community climate but are shaped by national climate and policies. For example, this project was created as a way to address a problem we observed in our city among marginalized communities affected by social, economic, and ecological inequity. The next set of factors in this model, the internal factors, we labeled community climate. While community climate is directly impacted by external policy related to equity, the internal social, economic, and ecological factors are defined more closely by perceptions of place and interpersonal networks (Pretty, 1990). In this case, the attitudes of residents in the neighborhood directly affect their children's eating habits and attitudes toward fresh vegetables. As we found during our harvest dinner, the few parents attending the event were not particularly receptive to the notion of eating fresh food from the garden, therefore, their children shared the same attitudes. The principles of risk and resilience and ecological theory are the most crucial part of community programming and measuring effectiveness. In other words, the key to alleviating the problems associated with food insecurity in our communities is reducing risks through educational programs like the Junior Master Gardener. The idea is the model will become a cycling of learning and growing.

As we learned from this experience, we discovered the old adage rings true; sometimes you "can't see the forest for the trees." As we expanded the program, added partners and key informants, identified additional assets in the community, we lost ground where we began; the Boys & Girls Club afterschool program. When working with community partners one of the most difficult tasks is to create a sustainable project without the presence of the "helpers." Recent changes in staff have resulted in neglect of the garden. While the project in the Housing Authority flourished and the refuge population grew beautiful gardens, weeds sprouted in the Boys & Girls club plot.

Our plan for the next few years is to maintain our relationship with the community and help financially support both the Boys & Girls Club and the Housing Authority gardening efforts. The residents in the community are a cohesive group who tend to work, learn, and play together. Our hope is to encourage healthy eating habits, increase access to local food, and educate children about where their food come from and why it is important to eat responsibly. As an extension of our current efforts, we are exploring the possibility of working on the issue of the "unbanked." One of local banks has agreed to teach children about finances and set up checking and savings accounts for those selling produce at local farmers during the summer months. As we move forward, our goal is to keep our emphasis on the children in the neighborhood; they are our future.

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Talcott Parsons: A Voice from the Past, an Opportunity Missed, and a Road Not Taken

John E. Tropman and Emily Nicklett
With Documentary Material from Talcott Parsons
(December 13, 1902–May 8, 1979)

Abstract: In this paper, the authors discuss the history of correspondence with the well-known sociologist, Talcott Parsons, in 1977 and again, just before his death in May 1979. A prolegomenon introduces Parsons, contextualizes the correspondence, and explains how the authors came to collaborate on this project, which seeks to preserve the history of this correspondence with a leading school of social work. The discussion begins with a brief introduction to Parsons, followed by each of the other's reflections on the project. There follows a section on Parsons himself and a note on the collaboration.

Keywords: Talcott Parsons, social work, sociology, AGIL model of social organization

Introduction

Talcott Parsons was arguably the most famous sociologist of the twentieth century. Sandro Segre's (2012) *Talcott Parsons: An Introduction* offers a recent discussion of Parsons' work, a periodization of his foci, and a discussion of the reception of his work in an extensive secondary literature. From Parsons' position at Harvard University he taught many students who became renowned sociologists in their own right, among them Robert K. Merton and Edward Shils. He was primarily a "grand theorist," but he also wrote about organizational structure in the context of such substructures and subcultures as the medical profession, the university, and the sociology of health and aging.

Tropman's Interest in Parsons

My interest in Parsons began when I was an undergraduate at Oberlin College taking an introductory sociology course taught by J. Milton Yinger. Yinger's interest in religious values, which explored the religious-based discrimination experienced by minorities in the United States, led me to Max Weber, and thence to Parsons. Simultaneously, I took a medieval and modern European history class with Bernard Silberman, who is now director of the Workshop on East Asia at the University of Chicago. Silberman was also interested in Weber and discussed his *Protestant Ethic and the Spirit of Capitalism* in class. This inquiry brought me back to Parsons and values again. So I read everything he wrote—much of it a slog. He seems to have thought in German and written in English, a hurdle for readers since English lacks the combinatorial/conceptual fluidity of German.

My interest was further piqued during a senior sociology seminar taught by Joseph Elder, now professor emeritus at University of Wisconsin-Madison. Elder had studied with Parsons at Harvard. During the seminar, Elder shared personal observations about Parsons, one of which stuck with me. Because Parsons was so popular, Elder recalled, he and other students (all taller than Parsons) encircled Parsons so that he could leave the lecture hall in peace. I contacted Elder to confirm the substance of the anecdote. Elder replied (personal communication):

> I will stand by the account you attribute to me about being part of a buffer (at least once) around Talcott so he could get from the lecture hall to his office. Another factor of the buffer might have been that a small group of us grad students were taking a "reading course" with Talcott about Max Weber. And the only way we were going to have our "reading session" with him was to extricate him from the undergraduates and the lecture hall and transport him back to his office.

Parsons' grand theory, which focused on the structure of social action, always held a certain appeal to me, since I am generally a big-picture person. His focus on values and their structure was of specific interest and influenced my later work. During the 1970s, I developed a grammar of values that I called a "conflict theory of values," a perspective that envisioned values in juxtaposed sets. By juxtaposed I mean abutting rather than opposing, like plus sign (+) rather than a minus sign (–). In fact, it was the achievement and equality tension, used in S. M. Lipset's *The First New Nation* (1963), which started me down the competing values path.

Using comparative and developmental analysis, Lipset compared early American society with emerging nations and their varieties of democracy. He took seriously the "concept of values as a constitutive part of the structure of society," and–of primary importance to me–focused his analysis on "the balance between … equality and achievement … against the background of a basic individualism." To do so, he analyzed critical cases of religious institutions and trade unions within the United States, and political development within modern industrialized democracies, including the U.S., as discussed by Parsons (1964, 374-375) in his review of the book.

Other value juxtapositions quickly revealed themselves, among them fair play and fair share in allocative processes; competition and cooperation in market orientation; clan and market style organizations; and adhocracy and bureaucracy in forms. Parsons positively reviewed an early concept paper exploring these ideas, which I later developed as *American Values and Social Welfare: Cultural Contradictions in the Welfare State* (Tropman, 1989).

Nicklett's Interest in Parsons

I (Emily Nicklett) became a Parsons enthusiast as a doctoral student. I was enrolled in Renee Anspach's "Sociology of Health and Illness" seminar at the University of Michigan. Through the process of preliminary and qualifying exams in Public Health and Sociology, I had become familiar with several of Parsons' theories. Anspach's presentations and facilitated discussions presented Parsons' work as a prominent chapter in the biography of medical sociology and social gerontology.

In an early chapter in the history of medical sociology, Hippocrates stressed the importance of the clinical case study for understanding the human body and patterns of disease (Oliver, 1925; Porter, 1999). Much later, Emile Durkheim (1951 [1857]) discussed how society and social change affect the health and well-being of certain individuals in society (in the case of *Suicide,* those individuals are white Protestant males). More recently, Parsons focused on the interaction between society and systems of health and illness. Parsons argued that society and these systems function only in relation to one another. For example, these systems identify clinicians as gatekeepers to "the sick role" (Parsons, 1951; 1975). These gatekeepers provide checks and balances to ensure society has a plentiful and productive workforce. Unfortunately for Parsons, what became known as structural functionalism fell out of favor among sociologists, who in turn approached health-related inequalities with conflict theory, post-structuralism, and postmodern approaches.

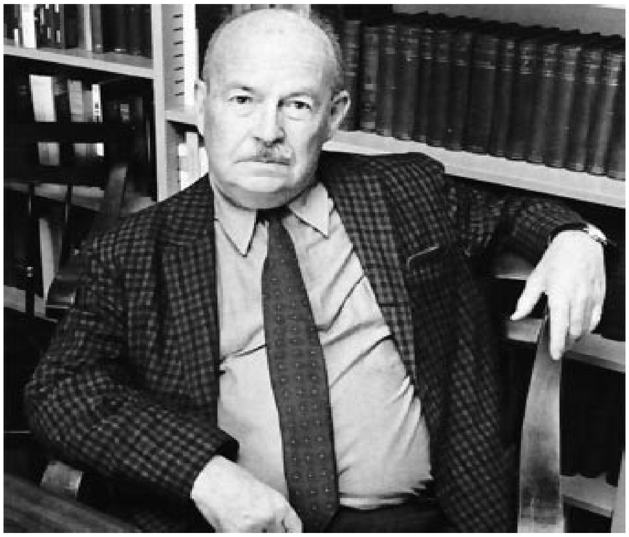
However, Parsons' contributions to the fields of medical sociology and social gerontology are as relevant as ever. The sick role–negotiated by clinicians and policymaker gatekeepers–remains the legitimate temporary relief from society's obligations, and competition for the label has grown more fierce. Societal changes, including higher healthcare costs, aging populations, and increased prevalence of chronic diseases, bring additional barriers to entry to the sick role, while the cost of and demand for the sick role have increased. Health and social systems continue to work together to regulate eligibility criteria for the sick role.

Parsons' sociological contributions should be taught to students interested in careers involving advocacy for individuals, communities and societies. Parsons' insight that social change is limited by parameters or norms, and that these parameters or norms are both shaped by the social structure and are resistant to change, is hardly controversial. Students of advocacy learn that it is necessary to identify barriers and facilitators to desired change, as well as to consider stakeholders in support of and opposition to this process. Our students need to characterize and understand social and structural barriers to change in a society that resists change.

How It Began

In 1977, I (John Tropman) secured a grant supporting a project entitled, "American Values and the Elderly," through which I explored the value sets of American seniors. Since Talcott Parsons had written on the life course, I contacted him and secured him as a consultant on the project. We arranged a meeting in Cambridge, Massachusetts.

In August 1978, I met with Parsons in his office at Harvard. He was a small man with a trimmed moustache, but he was a giant in sociology. To get a sense of his influence, refer to Gideon Sojberg's (2015) obituary of Walter Firey. (Firey wrote one of the best sociological books I have ever read: *Land Use in Central Boston* [1947]. Do not be fooled by the title.)



Parsons and I had a wonderful conversation. We explored American values, the elderly, the integration of a society's elements into its members' personalities and visa versa, his cautiously appreciative views of Robert Merton – Merton's approach was toward "theories of the middle range" – and Max Weber's *Protestant Ethic and the Spirit of Capitalism.* He was an excellent, if complex, conversationalist. His demeanor was courtly, formal, but interested and interesting all the same. And it was a conversation, a back and forth. I had no sense that this giant in the field was lecturing me or putting on professorial airs of any sort. Parsons' reflections on that meeting are detailed in his letter of September 25, 1978 (see below), and in our subsequent correspondence.

We laid plans for him to visit Ann Arbor – a first for him – after he returned from Germany in spring 1979. My public reason for suggesting the visit was to extend his consulting relationship with the American Values and the Elderly project: His work on the life course could contribute substantively to its development. My private reason was to interest him in a longer-term relationship with the University of Michigan School of Social Work and Department of Sociology.

I had an eye toward developing a sociology of the professions focus and, more particularly, a sociology of social work emphasis. This might have fostered an *interprofessional* focus that was parallel to but distinct from the *interdisciplinary* focus for which the University of Michigan was well known.

Though professionals frequently collaborate across professions in the contemporary workplace, they often train alone. The neologism interprofessionality points to the interaction of teaching, learning and scholarship between and among professional training centers; among them schools of social work and public health and policy, business, medicine, and nursing.

(Re)Introducing Talcott Parsons

Talcott Parsons (1902-1979) was among the preeminent sociologists of the twentieth century. A founding member of Harvard University's sociology faculty, he authored numerous books and articles, beginning with *The Structure of Social Action* (1937). He aimed to develop a unified theory of action that moved beyond the theoretical realm. It was a goal he never fully achieved, in part because of the book's large size and complex prose style. The sociological collegium seemed to prefer Robert Merton's "theories of the middle range," which sought to connect theory and empirical knowledge in specific areas that could then coalesce into a general theory. Merton commented: "We sociologists can look … toward progressively comprehensive sociological theory which, instead of proceeding from the head of one man, gradually consolidates theories of the middle range, so that these become special cases of more general formulations" (1949).

In spite of Parsons' interest in grand theory, he also had an interest in the sociology of specific sectors and fields, and it is this interest to which we turn. For us, his best and most accessible works remain his essays, most notably in *Structure and Process in Modern Societies* (1960) and *Social Structure and Personality* (1970). The former contains his famous essay, "A Sociological Approach to the Theory of Organizations," and the latter includes a series of essays on the fit between person-in-context, including "Stages of the Life Cycle" and "Health and Illness." These shorter works seem most timeless and accessible.

The Tropman/Nicklett Collaboration

Our collaboration arose from out of a mutual fondness for Parsons, and our common use of Parsons' AGIL table. Adaptation, Goal Attainment, Integration, and Latency (AGIL) Theory describes the social system as an entity that defines parameters or norms, and opportunities to change those norms. Due to the subsequent maintenance of the current social structure, the social system is resistant to change. Parsons' AGIL table helps identify barriers to making change. The "flow" of the table starts with adaptation and proceeds clockwise. Barriers occur as the flow from one cell into the next is impeded.

Although we have different foci (Tropman in management and leadership; Nicklett in aging and health), our Parsons connection emerged in conversation. We found ourselves working together around Talcott Parsons and the AGIL table. Nicklett worked with the table to examine life-course gerontology and Tropman sought to use it as a template for organizational change. As we chatted, we laughed often. We were relatively certain that we were the only people in miles who even knew what the AGIL table was. Tropman's interest was especially focused, as he examined two books on successful organizations: Peters and Waterman's *In Search of Excellence* (1982) and Collins' *Good To Great* (2001). These books chronicled similar experiences. Both books looked at the growth of successful companies (Goal Achievement in the AGIL Table), derived lessons from them, and then discovered that many organizations in the authors' "sample" crashed and burned (failure to integrate in the AGIL Table). Perhaps, for Tropman, getting to great and staying great are two different things.

We had many discussions about Parsons. One of the more striking elements we noticed was the amazing similarity between Parsons' AGIL table and Deming's Plan Do Check Act Cycle, evident in a review of Figures 1 and 2.

The only immediate difference is that Parsons began his table in the upper left, and Deming in the upper right.

Though a statistician, Deming was an intuitive sociologist, and he had a complete grasp of the concepts inherent in Parsons' integrated view of systems. That is, he grasped synthesis between and among organizational structure and culture (horizontal) and between and among levels of social organization (societal, communal, organizational, family/group, and personal).

Deming's system-based approach was very similar, if more modest. He focused on organizations and the need to understand that an organization's products depended on the whole organization. At a lecture of his that Tropman attended in Detroit, Deming argued that 75% of an organization's outputs depended on "common causes of variation" (integration of all parts and elements, or lack thereof). He also commented on America's over-fascination with "the individual" as opposed to the system.

Parsons and Deming's "integrative view" of "people in context" support and underpin a core element of social work's approach to problem managing and solving. Each of us uses Parsonian insights in our teaching.

Figure 1. Parsons' AGIL Model of Social Organization

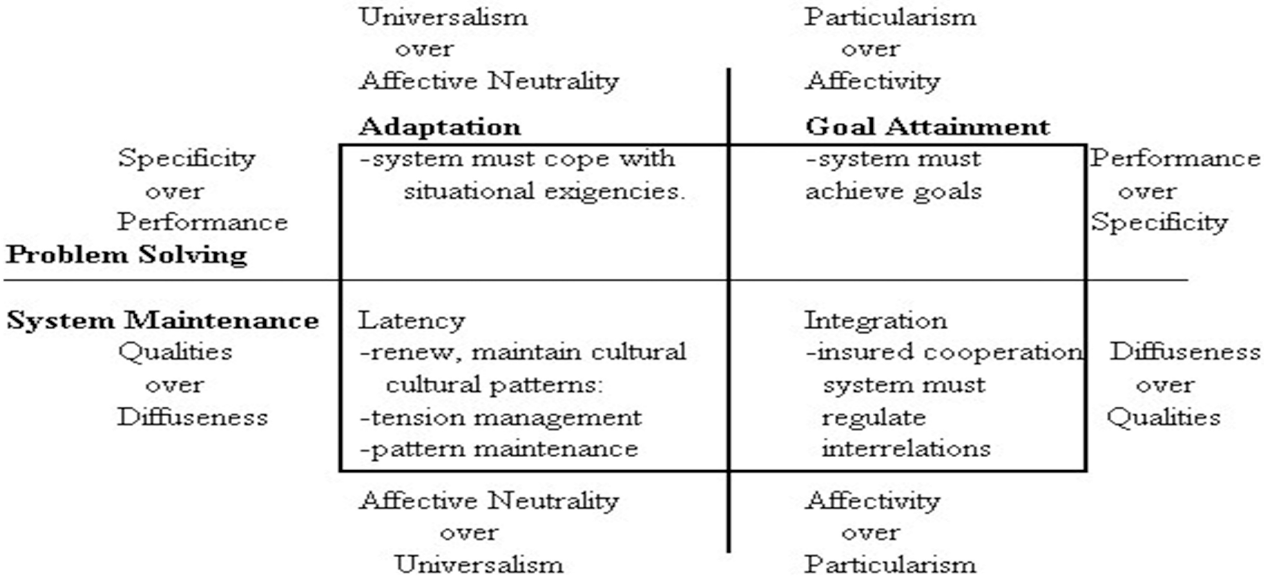
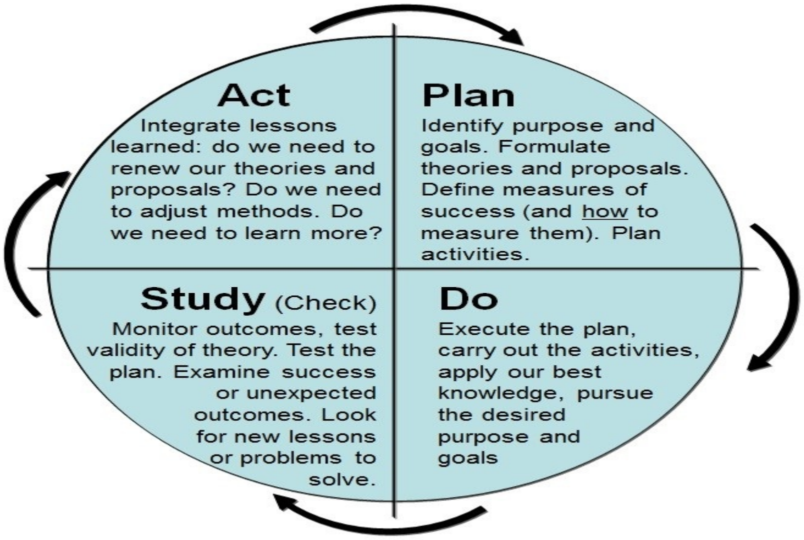


Figure 2. Deming's Plan Do Check Act Cycle



Act
Integrate lessons learned: do we need to renew our theories and proposals? Do we need to adjust methods. Do we need to learn more?

Plan
Identify purpose and goals. Formulate theories and proposals. Define measures of success (and how to measure them). Plan activities.

Study (Check)
Monitor outcomes, test validity of theory. Test the plan. Examine success or unexpected outcomes. Look for new lessons or problems to solve.

Do
Execute the plan, carry out the activities, apply our best knowledge, pursue the desired purpose and goals

After a fruitful collaboration, John Tropman and Emily Nicklett decided to seek publication of the Parsons-Tropman correspondence, and to discuss their appreciation for him for two primary reasons. One reason was simple historical interest in how the field of academic sociology developed. The other was connected with our shared interprofessional agenda: Each of us has disciplinary *and* professional backgrounds, shaped in no small measure by the broad range of Parsons' work.

We believe that, had Parsons visited Ann Arbor, the engagement might well have stimulated his–and the university's–interest in the sociology of the professions and their importance, both singly and severally, in the social structure.

Further, we suspect that the concept of *interprofessionality* might have emerged in conversation, especially in the University of Michigan soil of interdisciplinarity, and the fertile ground of the Joint Program in Social Work and Social Science, offered then and now, by the School of Social Work and five academic departments (anthropology, economics, psychology, political science, and sociology).

Who knows? Had that visit occurred, the University of Michigan might now offer joint doctoral programs between the School of Social Work and the School of Public Health, as well as the present interdisciplinary offering.

Table 1. The Parsonian Universe

THE PARSONIAN UNIVERSE All Parts and Elements Need to be Integrated		
	Social Structure	Social Culture
Levels of Social Organization		
Society		
Community		
Organization		
Families/Groups/Associations		
Individuals		

We might also have had the impetus to study the issue of professional confluence and succession. Bader's (2014) recent article, "Is the MSW the New MBA," might be a case in point. There, the author argues that the collaborative core of social work might be as important as, or in some cases more important than, the competitive focus of the MBA. But, one might ask, could not some of the initiatives we discuss here have been undertaken even without a Parsons visit? The answer is, of course, yes! However, our reflections illustrate what students of change have often observed: It is difficult to initiate change from within an organizational entity. Sometimes an outside *disruptive force,* a technology or behavior that fundamentally changes the way an organization does business, is needed. Investments in the *status quo* are powerful retardants to innovation. A visit from a world-famous sociologist with interest in the professions might have spurred us to think outside the box. The University of Michigan's missed opportunity to engage with, learn from, and apply the theories of Talcott Parsons in the context of professional training is indeed a loss.

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(Please turn the page for the correspondence)

The Letters

At the afternoon meeting in August 1978, Tropman and Parsons discussed the *American Values and the Elderly Project* [Editor's note: Tropman's book of that title] and the concept of conflicting values. Parsons was quite loquacious and a bit hard to follow, so Tropman asked him to summarize his thoughts. The September 1978 letter is a result of that request.

The letters are presented here in their original form. In many ways they are classic Parsons, with all of the circumlocution he was known for. His style is recursive, almost stream-of-consciousness. But he does touch on the life cycle, focusing especially on financial and health issues of the elderly as a part of the life course.

As an odd curiosity, Parsons was a guest at Keansei Gakuin University, the very school where Tropman had previously served as a Fulbright lecturer. His translator was Professor Saeko Murayama, now deceased, who was a 1976 graduate of the Joint Doctoral Program in Social Work and Sociology at the University of Michigan and had been one of Tropman's students.

HARVARD UNIVERSITY
DEPARTMENT OF SOCIOLOGY
William James Hall
Cambridge, Massachusetts 02138

May 21, 1979

Mr. John Tropman
Institute of Gerontology
The University of Michigan
520 East Liberty Street
Our Town MI 48109

Dear Dr. Tropman:
First, … I stressed …"instrumental activism…This in turn, it seems to me, can be translated" into the complex which has been called institutionalized individualism. …This has some bearing on the problem of the independence of individuals, but looked at complementarily, in terms of their capacity to contribute to what are in some sense socially and culturally valued concerns. The problem of the status of individualism is very deeply grounded in our cultural tradition.

I have been taking the formula **instrumental activism** to characterize the most general value pattern institutionalized at the societal level. As you are aware, I tend to derive this particularly from the ethic of ascetic Protestantism as analyzed by Weber but without special stress on the economic field of application.

Under that, I would speak of two directions of further development. One of them is what I have called specification to more and more concrete levels. As I developed it, as you will remember, the formula instrumental activism was meant to apply to a society as a whole. If one speaks, however, of the values institutionalized in an occupational role this is at a very much lower level of specification. Even if the concept role does not apply only to a specific individual but to a category of roles assumed by individuals, still one type of occupational role is one among many types of roles in the society as a whole and roles are not the only components of institutionalized structures in a society. You will remember I have tended to treat the other three as collectivities, norms, and values. Specification is a matter of how the value pattern articulates with other three components of social structure at the requisite level of specifications.

The other direction of elaboration of development is that of functional differentiation. . The mode of rationalization, however, which applies to a family unit and the relations of its members to each other, should be, in my opinion, carefully distinguished from two other particularly common rationalities.

A second and the one which Weber stressed in his famous essay is usually called economic rationality. I think of this as focused on the orientation of acting unit – individual or collective – to one or more market situations and the measure of rationality has to do with costs and benefits evaluated in terms of money.

Still a third field of rational action is the cognitive, which Gerald Platt and I have made the centerpiece of our study of the American university [editor's note: *The American University*]. We think of the university as a collectivity-type, which is focused about the implementation of a particular set of values of rationality – those having to do with the generation and transmission of knowledge. Of course, differentiation of types need not apply only to the sectors of the society in which values of rationality are paramount but another set is conspicuous in such fields as style of life, the arts, and perhaps one may say, religion, although "rational theology" is by no means unimportant in the latter set.

I would like also to call your attention to the fact that the concept which I have used of **value-generalization** should be regarded as the obverse of specification, as referred to above. The fullest exposition of this concept can be found in the essay entitled "Comparative Studies and Evolutionary Change," which was reprinted as chapter eleven of my volume of essays entitled *Social Systems and the Evolution of Action Theory.* This concept is based on the assumption that in the course of social evolution, in the early stages the generalized value patterns corresponding to instrumental activism are couched at rather low levels of generalization and that one necessary feature of an evolutionary process is to redefine them at higher levels of generalization. Just to take one example: it seems to me that the step in Western religious history of Judaism to Christianity constituted such a step in value generalization, as did in a much more secular sphere the step in socio-economic development which centers around the Industrial Revolution and which included above all labor as a factor of production in the market system on an unprecedented level.

This (line of thinking ed.) leads over into another, but closely related, set of considerations. It seems to me that sociological consideration of the state of relatively contemporary American and other industrial society has focused very heavily on stratification on the basis of social class. There has been good justification for this emphasis but I think it tends to obscure the emergence of certain other themes. The most important single rival to social class has been, I think, **ethnicity**. And they have to a considerable degree historically tended to be correlated though I think this correlation has diminished rather rapidly in recent decades.

However this may be, I think what we have been seeing is a strong tendency to the emergence into prominence of a third basis of stress and emphasis which focuses in what we may call the Gemeinschaft area of the social structure. Using the old anthropological-sociological formula, I would speak of this as the complex concerning "age and sex." The earlier emphasis in this field has been on the earlier phases of the age structure. I think it is correct to say that it first involved a heavy emphasis on the importance of child training which was the focus, you will remember, of the "culture and personality" movement which centered in social anthropology but in a certain alliance with psychoanalysis. The focus of interest gradually moved upward in the age scale. A second major phase was focused on problems of adolescence.

Then came the phase of what I have called the educational revolution, which involved after World War II the enormous expansion of the system of higher education. Naturally a tension could hardly be denied when there erupted in the later sixties the pate of student disturbances which is green in all of our memories (you don't have to be nearly as old as I am to have vivid memories of that). You may remember that Platt and I in our book on the American university coined the concept "**studentry"** because we felt that this was not a phenomenon essentially of adolescence which focused at the secondary school level.

It seems to me that we have recently been seeing still another phase of this developing focus of interest in the emergence of gerontology and whole study of aging and the elderly. I happen to agree very much with my friend Matilda Riley's emphasis and that of her associates **that aging should not apply as a concept only to the later phases of the life course, as they call it, but that it begins at birth if not at conception.** This to me is to say that the problems of the elderly should be seen in the context of consistent analysis of the whole individual's life course from birth to death. I presume that this perspective is very congenial to you and your group.

Since seeing you, I have read a draft paper by Matilda Riley which is to be published I think in the next issue of Daedalus. [editor's note: Matilda White Riley, "Ageing, Social Change and the Power of Ideas," in *Daedalus* 107(4), pp. 39-52]. This is, I think, her most theoretically systematic attempt so far to pull these things together and it proved to be an exceedingly suggestive paper for me. What it seems to me has been happening is that the age-sex complex, as I have called it, has begun to occupy the center of societal concern in a sense in which that was not true a generation and more ago. At least relatively this is leading to a downplay of the previous stress on social class on the one hand and ethnicity on the other. The very fact that college students could be the focus of a major set of disturbances quite comparable in national "seriousness" to waves of strikes or to race riots seems to me to be one major symptom of the change I have in mind. The bases of this change constitute major themes of the book I have been working on, which I think I mentioned to you.

It very much concerns our attitudes toward the elderly because, after long and major sector of the life course the problem arises, Well, what are our attitudes toward these persons who have reached this particular life situation? From one point of view differentiation between saints and reprobates put in the Puritan terminology, or the deserving sector of the population and the undeserving sector. I don't think it is quite that definite and simple.

This leads to the exceedingly complex problem area of the relations of work and leisure [editor's note: He is referring here Chapter 3 in John Tropman, *American Values and Social Welfare*, 1989. Englewood Cliffs, NJ: Prentice Hall.] From one point of view, work is considered decidedly meritorious and leisure is the earned reward for meritorious work. However, it is not possible to make things as simple as that. You and I discussed at some length the reservations that various "elderly" people, including myself, have about the life of leisure.

We then turn to problems of the significance of human mortality and the death complex. I reviewed the three ventures that I have made in collaboration with Victor Lidz and also Renee Fox into the analysis of the symbolism about the currently popular view of the "denial of death" in American culture. It seems to me from my own self-observation and that of other elderly persons that we are not simply "waiting to die" and we are not obsessively preoccupied with the fact that eventually we must die, which of course is as fact taken for granted.

As contrasted with this feeling I would strongly emphasize the continuity of the various phases of the life cycle. There is a long series of transitions from one to another phase, such as from early childhood to what Freud called latency, from that to adolescence, from adolescence to studentry, early adulthood, and so on. We can, as your group has done, make use of Erikson's schema of life cycle phases. There are, however, certain basic continuities at least once the main orientations have been settled as in Erickson's concept of identity. I think most "normal" adults achieve certain stabilization by early adulthood which follows them through in the various world contacts in which they have to participate.

Let me now comment briefly on two somewhat different issues. **In our personal discussion,** you remember that I expressed that it did not seem to me that the anxieties and fears of the elderly were nearly so much focused on death, leading to the famous "denial of death" hypothesis, but that they rather concerned anxieties about incapacity and disability. As you know, I have strongly stressed the importance of the demographic changes which have occurred in about the last century as a result of which there are very greatly reduced numbers of what Victor Lidz and I called adventitious deaths and a greatly increased proportion of the age cohort who live into the stages of life which tend to be called elderly. This, of course, means that having survived the most important exposure to infectious diseases and having better food and hygiene than formerly, the elderly are increasingly exposed to what have sometimes been called the "degenerative diseases," many of which do impose disabilities although people afflicted with them are often not immediately threatened with death. Vascular difficulties would be a major field to cite for them.

Also, as you know, I would strongly stress the importance of certain aspects of individualism in our society and culture and one major focus of this is the high valuation of personal independence. The fields in which this becomes important and the way it does are exceedingly various and there are many subtle complexities.

However, there is a particular relevance of this set of considerations to the status of the elderly. Much of the discussion previously has centered on the financial aspect of dependency, which, for example, underlays the development of the Social Security system in which the pensions for retired people constitute by a good deal the largest component.

I think we have recently been seeing an important shift away from the emphasis on the financial problem of the elderly to **the capacity problem** which is of course very much bound up with health. The surfacing of this problem at the national political level in the recent act of Congress on retirement problems seems to me to be a very important symptom of a set of changes which have been going on. I think we covered this area fairly thoroughly in our discussion. I would merely like to re-emphasize that I consider it as very substantial importance.

These are some of the main theoretical considerations that your program suggested to me. I hope they will prove stimulating to you and your group. I think the practical problems have been dealt with in the insert above at the beginning of the part of the memorandum I have dictated today.

Sincerely,

Talcott Parsons

Talcott Parsons

University of Michigan
School of Social Work

November 30, 1978

Professor Talcott Parsons
Dept. of Sociology
Harvard University
Cambridge, Mass 02138

Dear Professor Parsons:

I hope that this note finds you now returned from a successful visit in Japan, and that the trip was a positive one for you and your wife. Our staff found your comments most useful and are proceeding to some thinking along the values system lines you suggested in your letter. I do hope that we will have the occasion sometime after the first of the year to have you be a brief guest here in Our Town. At that time we could discuss the possibility of a short piece which might be included in our anthology, but would give you the opportunity to share some of your thoughts on the social system and the role of the elderly in that social system. One point of departure might be the concept of institutionalized activism which we discussed at the meeting in August. I hope, by the way, to be East this summer – the Cape again and Vermont. I mention it now in the hope that I have that we could meet during that time at your convenience.

With all personal regards, I remain,

Sincerely yours,

John E. Tropman, Ph.D. Research Scientist
JET/

HARVARD UNIVERSITY
DEPARTMENT OF SOCIOLOGY
William James Hall
Cambridge, Massachusetts 02138

March 27, 1979

Professor John E. Tropman, Ph.D.
Institute of Gerontology
The University of Michigan
520 E. Liberty Street
Our Town MI 48109

Dear Dr. Tropman:
Thank you very much for your letter. I am very glad to be in touch with you again. You ask two very practical questions to which I think I can give quite specific answers.

The first is about the possibility of coming to Our Town for a day's conference. In principle, I would be glad to do that, but must impose certain time schedule constraints on the proposal. Just a month from now, I am taking off for what in turn will be another month's trip in Western Europe. I have enough obligations coming up before my departure for Europe, so it would be out of the question for me to try to fit in a trip to Our Town before that departure. This means I would not be available before quite late May or early June. To complicate matters further, I have agreed to go to Salzburg, Austria, to attend the annual meeting of the World Federation for Mental Health which is scheduled to run from July 8 to 13. The period between late May and early July is none too long, but it could well be that a visit to Our Town could be fitted in during that period. If not, it would have to be postponed until after the middle of July.

The second question is whether I would be willing to contribute a statement or a chapter or a memorandum for your proposed publication on the problem of values and the status of the elderly in American society. I think I would be very glad indeed to do so, provided that there would not be a deadline which would obligate me to deliver a manuscript before the end of the summer or the early fall. I am very glad that you referred in your letter to Professor Murayama [Editor's note: This is a reference to Saeko Murayamar, who received her Ph.D. in Social Work and Sociology from the University of Michigan in 1976]. I saw a good deal of her during my stay at Kwansei Gakuin University. Indeed for my formal lectures, she was my senior official translator and served me very well. I had very pleasant and cordial relations with her and here in Massachusetts I record my professional engagements in a calendar entitled "Beautiful Japan 1979", which she kindly presented me with when I was about to leave Japan. I value my association with her greatly.

Sincerely,

Talcott Parsons

Talcott Parsons

HARVARD UNIVERSITY
DEPARTMENT OF SOCIOLOGY
William James Hall
Cambridge, Massachusetts 02138

April 26, 1979

Ms. Jane McClure [Editor's Note: Ms. McClure was on the staff of the American Values and the Elderly Project.]
Institute of Gerontology
The University of OurUniversity
Our Town MI 48109

Dear Ms. McClure,

Thank you for your note. I think a visit to Our Town around June 7th or 8th would be entirely satisfactory from my point of view. Of the two days, I think the 7th would be preferable since I would like to be back here on the Friday with the weekend in view.

I am starting out on the European trip I mentioned to Dr. Tropman this coming weekend. I expect to return on Sunday, May 20th. I presume that would be time enough to be in touch about het more specific arrangements. You can reach me by telephone on Monday or Tuesday of that week or write a letter which will be waiting for me on my return.

Sincerely,

Talcott Parsons

Talcott Parsons

HARVARD UNIVERSITY
DEPARTMENT OF SOCIOLOGY
William James Hall
Cambridge, Massachusetts 02138

April 26, 1979

Ms. Jane McClure
Institute of Gerontology
The University of OurUniversity
Our Town MI 48109

Dear Ms. McClure,

Thank you for your note. I think a visit to Our Town around June 7th or 8th would be entirely satisfactory from my point of view. Of the two days, I think the 7th would be preferable since I would like to be back here on the Friday with the weekend in view.

I am starting out on the European trip I mentioned to Dr. Tropman this coming weekend. I expect to return on Sunday, May 20th. I presume that would be time enough to be in touch about het more specific arrangements. You can reach me by telephone on Monday or Tuesday of that week or write a letter which will be waiting for me on my return.

Sincerely,

Talcott Parsons

Talcott Parsons

HARVARD UNIVERSITY
DEPARTMENT OF SOCIOLOGY
William James Hall
Cambridge, Massachusetts 02138

May 21, 1979

Professor John E. Tropman, Ph.D.
Institute of Gerontology
The University of OurUniversity
520 E. Liberty Street
Our Town MI 48109

Dear Professor Tropman,

Mrs. Parsons asked me to write to you and say that she knew Professor Parsons was looking forward to meeting with you in Our Town next month.

Sincerely,

Cathy Perkus

Cathy Perkus