Illuminating the invisible voices in mental health policymaking

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Abstract In public mental health policymaking, the inclusion of numerous stakeholders across lay and professional communities is expected. How the voices of these stakeholders meld to create a single unifying accounting of their actions and recommendations for policy is often unexpected. Unexpected in that, while all voices are important and participation often mandated, what is incorporated into the formal accounting of the policymaking process often does not reflect the elements of services that work most successfully for persons with mental illnesses and their family members. In this paper, I show how existing agendae of members of public policy task forces recontextualize the stories of persons with mental illnesses and their family members to reify societal expectations of these stories. I offer suggestions on how these stories should be incorporated into task force reports to further the development of appropriate policy and services that meet the needs and expectations of persons with mental illnesses and their family members.

Keywords Stakeholder voices · Patient narratives · Mental health services policymaking

Introduction

In public policymaking, particularly in mental health policymaking, the inclusion of numerous stakeholders is expected. However, how the voices of the stakeholders

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meld to create a single unifying accounting of their actions and recommendations for policy is often unexpected. Unexpected in that, while their voices are important and participation often mandated, what is incorporated into the formal accounting of the policymaking process often does not reflect the elements of services that work most successfully for persons with mental illnesses and their family members. Hence, the public meetings (live and online), testimony, minutes, press releases, and the final reports all illustrate the consequentiality of communication, as we examine the procedures, dynamics, and structures of communication among a multi-stakeholder group addressing changes in a state mental health delivery system. I further suggest the stories of persons with mental illnesses and their family members are often recontextualized to suit existing agenda that the writers of the final reports keep hidden from themselves.

Why do I study public policymaking from a communication perspective?

As the director of the Research Library of the Florida Mental Health Institute (FMHI), I provided research services to faculty and research staff from 1990 to 2011, with a particular focus on health services research and policy. I conducted reviews of the literature, wrote policy analyses, identified trends and impacts, and did my best to support the mission of FMHI: "to improve the lives of people with mental, addictive, and developmental disorders through research, training, and education." Of the many policy issues I have researched, how a policymaking body decides and recommends a course of action is the most fascinating.

In 1999, the Florida Legislature identified a problem, i.e., that the state mental health system had not been

systematically viewed for over 15 years. Further, during that time, numerous innovations and changes in clinical practice had occurred. The Legislature requested (1) a systematic review of the state mental health services and substance abuse services systems and (2) recommendations to increase the efficacy of the state's investment in the provision of said services. Hence, the Legislature wrote House Bill 2003 (HB 2003) and created the Florida Commission on Mental Health and Substance Abuse.

Since the Chair of the Commission, David Shern, was also the Dean of FMHI, the daily operations of the Commission were conducted there. Dean Shern asked me to provide research support services to the Commission. In addition, I was to archive documents on a publicly available website. Working on a public policy question was not new to me. I was involved already in the preparation of a series of reports to the legislature on the topic of mental health parity at the request of Florida Senator John Grant. However, this assignment was innovative. Not only would I be posting Commission-generated information, I would also be posting materials received by the Commission from the larger mental health community and making available the videotapes of the Commission meetings.

When I first began working at FMHI, it was a residential treatment facility for adults and a day treatment center for adolescents and children. I worked daily with our clients when they came to the library or when I went to the units to bring a book truck to those individuals who did not have off-unit privileges. Since many of the clients were long-term residential clients, they saw the library as a safe haven and its staff who were "like normal people," like them. They became friends. I knew their names, what they liked to read, and often their past and their hoped-for futures. I saw them at the cafeteria where we all ate. From our conversations, I learned that mental illness has many meanings. For each of them, trauma, deep-seated fears, and vulnerabilities emerged with the experience of mental illness. Some of their fears related to what they were afraid of losing or had lost already: jobs, families, themselves. I also saw how quickly a normal conversation changed into a crisis-handling conversation when a client had a psychotic break, off-unit. He or she would be gone from the library for days, weeks, or months. Sometimes they would be "like normal" when they returned; sometimes not. Either way, I celebrated with them their regaining of off-unit privileges with their return to the library.

As a librarian, my research interests lay in classification and cataloging. I classify and categorize, by name, subject, and authority, naming and creating relationships among things, individuals, and institutions. However, categorization is also about understanding the attributes, the "why" of the naming and relating of things. The knowledge that is associated within a category is so culturally shared that the simple mention of a category, such as "a person with mental illness" or "mental health professional," produces expectations of what the persons belonging to it are like and how they should behave.

I also know how simple it is to transition the focus from person as the 'object' of treatment to person as the individual choosing a particular action. Words have power to engage us in actions and understanding. The explicit and implicit expectations of the categories of PERSON and TREATMENT frame how helping professions, persons with psychiatric disabilities, and how social services systems operate. These categories also frame the information necessary for each group, as institutions—current and historical, to operate and to know.

I began to investigate the architecture of services and the roles of those who participate in its design and construction. My work on mental health parity took me into numerous community mental health communities. As I worked with advocates, family members, and peer-run groups, the lines between "helping professional" and "consumer" blurred. Writing the parity reports for the Florida Legislature, I struggled to retain the significance of individual accounts, without reducing the layers of complexity of the individual and where he or she was situated to a single generalizable statement. If the personal accounts and the scientific accounts made sense to me, how could I ensure it made the same sense to the legislators who held the power to improve the daily lives of persons with mental illnesses.

Amanda was one of the first people I met who was on the residential unit at FMHI. She was 48 when I met her. She had literally been in and out of institutions for over 30 years, after her first psychotic break. Her story is similar to so many of the stories I have heard over the years: their lost dreams of finishing high school, of college, of family, of having a job, of living in their own place; the hope all of them had that this time the treatment would work, that they could have the life they wanted. I listened. I helped them find books and articles on treatment, on jobs, on anything they asked about. I provided a supervised work environment so clients could gain skills and knowledge. I wrote letters of recommendation. I trained clients in how to use the library to find information. When the residential units closed in the mid 1990s, I provided the same supports to our clients in FMHI's community treatment programs and began an active program of research and teaching. Then the Commission was created and my interest in the formation of mental health policy grew. When I entered into the graduate program in the Department of Communication at the University of South Florida many years later, I gained theoretical and analytic knowledge that eventually would allow me to "make visible the invisible" process of policymaking.

Why this particular topic? Over the past 20 years, I have learned the distinction between recovery of mental health versus recovery from a mental illness. I have seen first-hand and been involved in the efforts trying to change the system. I believe in improving the quality of life for persons with mental illnesses. It is a mission of hope, a mission of consequence: a mission I support in my work at the College of Behavioral and Community Sciences and in my studies, first as a student in the Department of Communication, and now as a Communication scholar.

I see many benefits of this twinned approach. First, a communication framework helps me rethink the roles that practitioners and academics play in generating knowledge in the field. Second, I have new ways of thinking about the social languages and user constructs that are important components in the design and implementation of services. I gain an appreciation and tolerance of our different world-views, interpersonal styles, and contributions to research or community. Third, and however, perhaps the most important contribution is the opportunity to improve conditions and outcomes related to health and well-being, not just individuals, but of entire communities. Hence, my interest in how policy is made.

Black boxes and consequentiality

Hajer [1] suggests public policymaking is a "black box." People, time, effort, and energy are put into the box, the top is closed, and voila! Policy is created. However, I suggest a discursive approach which shows us how participants in the public policymaking process jointly contextualize, situate, and construct meaning and a shared understanding of the issues before them. The analysis of discursive practices within public policy allows us to examine how discourses are contextualized and which discourses, events, and practice are privileged or excluded [2]. I prefer a communication approach that focuses on language in a social frame, whether it is in conversations, narratives, and storylines, or as meta-discourse, the language we use when we refer to our own thinking and writing as we think and write [3]. Language in a social frame can be simultaneous (real-time) or contemporaneous (reflective) events, each informing the other. With no discrete boundaries, or discourses form human history. Through discourse, we can account for the ways in which participants construct their views, the subtle differences found in the expression of their views, and insight into the ideology or belief system of stakeholders and actors [4, 5].

Sigman [6] reminds us of that what persons do during social interactions has an impact on their lives, the institutions in which they work or use, and the relationships they establish. This 'consequentiality of communication' resides in "the ebb and flow" of talk where individuals engage in continuous negotiation and renegotiation of the production of meaning and shared understandings. Consequentiality of communication examines the larger process of communication, it a consideration of the "procedures, dynamics, and structures of communication," not necessarily just of the end results [6].

In 1999, the first-ever report on mental health by the US Surgeon General emphasized the expertise brought by consumers, family members, and advocates. The Report recontextualizes almost 30 years of the consumer and family movements into its discourse of science. During the 1970s, the families of persons with mental illnesses began to organize as a response to deinstitutionalization, to decrease the stigma associated with mental illness and to improve health at an individual and collective level. In 1979, family members formed the first chapter of what would become the National Alliance on Mental Illness (NAMI), in Madison, Wisconsin [7]. By 1981, the family member movement was gaining national attention [8]. By 1999, the influence of family members showed in the increase of consumer representation on federal and state mental health planning councils. Although the 1963 Community Mental Health Center Act had a provision for citizen participation, later federal laws, particularly the 1986 State Comprehensive Mental Health Plan Act and Public Law 102–321, mandated citizen participation on state and federal mental health planning councils for councils to receive federal funding.

The Florida Commission on Mental Health and Substance Abuse was created in 1999 by House Bill 2003 for the purpose of conducting a systematic review of the management of the state's mental health and substance abuse system. The legislative language of House Bill 2003 recognized the importance of the consumer voice by the inclusion of a family member on its membership roster for the Commission. The Commission included both a consumer and a family member in its membership. It further gave weight to the consumer and family member voices through invited and public testimony.

Although this brief recounting of the importance of consumer and family member inclusion in policy and services appears to suggest that their voices are heard and utilized to inform policy, it is in a close read of the end results that we may illuminate how their voices are hidden. I use two examples, one from the public testimony at a statewide public mental health policy commission meeting, and the other from the final report of the commission. In the first example, I examine the differences between Ruth O'Keefe's accounting of the mental health system and how it was reported in the Commission content notes. In the second example, I examine the vignettes of selected individuals who represent 'voices' from the stakeholders and

show the differences between their 'accounting' and their accounting.

Entextualizing and recontextualizing

When Ruth O'Keefe, who is a JD, MBA, CPA, and a family member of a person with a serious mental illness, was invited to speak to the Commission on 28 February, 2000, she told of her son's experiences as a person with chronic paranoid schizophrenia and the impact this illness had on her family. Ruth's choice of narrative provides two types of accounts. At a macro-level, Ruth shares her identity(ies) within the community of family members with the Commission; at a micro-level, it is a metadiscursive strategy, which achieves persuasive objectives through the establishing of the speaker's identity in relation to the hearer. Ruth's choice of a narrative uses the first person singular pronoun to index and position her as the speaker as well as to indicate her level of personal involvement and commitment.

Her story is incredibly difficult to hear. She relates the confusion and terror she and her family experienced with Christopher's diagnosis. However, she also speaks simply of the importance of the supports the mental health system is able to provide. When Christopher began experiencing psychotic breaks at the age of thirteen and throughout his teen-aged years, he was able to be safely housed and treated at a secure residential facility near their home, not a jail, "thank god the police took Christopher to University Medical Center where after a long time he was correctly diagnosed with schizophrenia. I am infinitely grateful that the police were taking my child out to the hospital and not taking him to jail." Further, the safe haven he found was also instrumental in his recovery from each psychotic break, "the most improvement I saw in my child was when he stayed at the Northeast Florida State Hospital because he was there long enough to be able to recover and it is an exhausting and traumatic illness." Christopher was able to complete and receive his GED, or as Ruth explained, "when you have a brain disorder like schizophrenia that is a thought disorder truth that getting his high school equivalency is just a major miracle".

Ruth's testimony was summarized and entextualized into the content notes by Commission staff, who were employees of the Florida Mental Health Institute at the University of South Florida. I suggest that the key element of 'reporting' in content notes is to provide an accurate accounting of the testimony of the participants. This may be problematic based upon the frames the reporter brings to the process. In the case of the Commission staff, the overarching frame should be around what services work and what services do not. This information is central to recommendations geared toward improving mental health services delivery.

The note-taker and I heard the same story. However, our 'take-aways' from Ruth's story are very different.

In the content notes, the note-taker, who is a mental health professional, recorded that Ruth spoke of her professional credentials, that she is proud of her two sons, one of whom who has chronic paranoid schizophrenia but who received his GED, the trauma of mental illnesses, especially the physical attacks on her and her husband by her son, and the death of her husband, brought on by the stress after one of these attacks.

I heard safe, secure residential settings for acute crisis intervention and long-term recuperative care are important. I heard crisis intervention skills for police responding to mental health emergencies are important. I heard there are problems with diagnosing mental illnesses and that accurate diagnosis and treatment are important. I heard a focus on who the person is and that they have their future, e.g., finishing a high school education equivalency degree. Yes, I heard the sadness that so often results from debilitating diseases. However, I also heard what works, from a mother's perspective. For me, Ruth is not reporting her life as a family member only as a sympathetic event, which is the tone of the content notes. She is doing much more.

She is negotiating the meaning for the Commission, shifting the dominant cultural conception of illness away from "victim of disease" to action. She is re-constructing a reality of mental illness to an action-oriented reality as her story shows the actions she and the system have taken on her child's behalf. Ruth's account provides a factual discourse in which she manages causality, agency, and accountability in mental health services and makes it relevant in talk [9]. Ruth's narrative attempts to address the contradictory and ambivalent nature of everyday sense-making practices around the stigma and treatment of mental illnesses. However, I suggest that the content notes are an example of how everyday language practices reproduce and legitimate relations of power. In her testimony, I also see hope, a hope that her voice can effect necessary changes in the delivery of mental health services, for the sake of all families coping with mental illnesses.

As the Commission came to the end of its year-long charge, work began on its Final Report. It began with a letter to Governor Bush, Senate President McKay, and House Speaker Feeney. An executive summary, a history and overview (Chapter 1), findings (Chapter 2), and recommendations (Chapter 3) followed. The report concluded with a copy of HB 2003 (enabling legislation), a dissenting opinion, and references. Accompanying the Final Report was another text, the compilation of the four workgroup reports.

Kaufer and Carley [10, 11] suggest there is a historicity in the "literate practices and print as sociocultural constructions" by groups. Although the Commission was comprised a diverse group of stakeholders, the Commission is described as "made up of diverse professionals from throughout Florida". Further, there is no formal mention of the role consumers and family members played in the development of these recommendations, "the body of this report is a synthesis of the extensive work done by the workgroups and the full Commission". It is not until Chapter 2 of the Final Report (findings) that the voices of consumers and family members are invoked.

This chapter incorporates quotations by and descriptions of persons involved in the mental health services system in Florida. Eighteen voices are used. Nine are direct quotes from professionals, five are direct quotes by consumers, and five are stories about consumer experiences in the third person. Although the professional and the lay communities appear to be represented fairly equally, I argue there is a significant difference in the use of their voices. According to the Surgeon General's Report, there is the tacit assumption that both professional knowledge and lived experience contribute to expert and evidentiary status. However, in Chapter 2, there are significant differences in the display of these voices and in their representation. Professionals are given quotes, speaking for themselves, in the first person. Their authority is shown with the inclusion of their full name, their professional titles, and institutions. Of the ten consumer quotes, the authority of the quotes is greatly diminished. Full names are not used. There are no professional titles or work affiliations.

Two quotes are attributed to 'Consumer'. Three are first person accounts, beginning with the inevitable frame of "My name is <insert name> and I have <insert disorder>." Five of the accounts are told in the third person, indirect reported speech. Of those five, only in one does the subject of the story have his voice. It is also the only story of the five that has a 'happy' ending ("I have a normal life now, and I'm proud of that"). The other four stories end in death or quiet desperation.

Like Ruth's entextualization in the content notes, the reader must 'push' through the sadness and lack of hope that are conveyed in these stories to find the relevant service and service provider that are worth keeping in the state service system. This is not to say that first person accounts are not valuable in showing the effects of mental illnesses or to illustrate problems in a state system of care. Oftentimes these narratives will be what is noticed, and repeated and used to emphasize that there are problems that result in human suffering and a diminished quality of life.

Although I write of a report generated in 2000, the same issues are still problematic in numerous state and federal reports, as well as reports generated by consumer and advocacy organizations. Yes, consumer voices are there. However, I question whether those stories that are reported contain the messages that consumers want to be told.

"I came. I told my story. They cried. Nothing changed."

Framing, footing, and alignment are ways to examine social roles [12, 13]. They offer insight on how speakers signal social roles and position themselves vis-à-vis one another during interactions. Frames are mental constructs that shape the way we see the world. Objects or elements within the frame are related to one another vis-à-vis their footing (i.e., where they figuratively stand in relation to the other). There are times where individuals need to shift frames within a social interaction. This is accomplished by shifting their footing, that is, the stance or alignment a speaker takes in relation to another.

I suggest that in policy reports to change the system, consumer suggestions, not pathos, should be in the forefront: a better trained workforce, supported services in a community-based setting, transitional services, increasing access to mental health and addiction services across all services sectors, and better screening and assessment. Policy reports would be better served by giving equal weight to both the professional and consumer viewpoints, both in the substantive content and recommendations of a report and by addressing higher-level policy concerns.

As Austin [14] reminds us, we "do things with words." Words in legislation implement service provision, afford protections, or regulate societal and individual behavior. Words in formal deliverables are accountings. Words from public and invited speakers contextualize an issue for the audience. When we, as academics, work on policy issues, we need to take a moment and step back in a reflective mode, weighing what elements of talk we prefer or disprefer, which aspects we put forward and which we choose not to hear.

Over the past 20 years, I have been privileged to work in a mental health research institute where the framing and investigation of public policy problems are de rigueur. I am reminded daily of the inherent difficulties in cross-walking among the disciplines, praxis, and theory that make up the social construction of mental health services delivery, mental health research, and mental health policy. Each name or representation, "relationally defines the person making the representation and constitutes the group of people" in a distinctive way [15]. As institutional and social languages become shorthand, this shorthand influences stakeholders across political and societal dimensions.

Why should we care? Perhaps the better question is, "How can we not care?" Mental health policy talk is not merely rhetoric. Fourteen percent of the global burden of

disease is attributable to mental disorders [16]; four of the top ten causes of disability in the world are mental illnesses [17]. Yes, mental illnesses are traumatic, horrifying, debilitating, chronic, and stigmatizing, resulting in increased mortality and morbidity. However, the illness is not the person. The person is not the illness. The illness is not the issue, it simply is. The issue is: what does the person need that policy and legislation can address—treatment, prevention, intervention, community services, resources, continuity of care. This can be done through a discursive process, of negotiations of claims, stakes, identities, and competing visions. As a parting thought, the Surgeon General's Report identified stigma as the biggest obstacle for reforming mental health. I would suggest that each time the pathos of mental illness is reified, we reinforce stigma. In addition, we hide the voices of those individuals who can tell us what works and what does not in dealing with the everyday reality of mental illnesses.

Conflict of interest   None.

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