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‘Wrong parents’ and ‘right parents’: Shared perspectives about citizen participation in policy implementation

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ABSTRACT

Government policies, both in Europe and the U.S., increasingly mandate that community-based citizens partner with professionals to plan and implement policy-relevant programs. In the U.S., parents of children with serious emotional disturbances may participate in Community Collaboratives which are charged with implementing children’s mental health policy in local communities.

This qualitative study examined three Community Collaboratives and identified organizational features associated with how the groups prioritized lay involvement, among other competing goals which they legitimately could pursue. Thirty-four key informants participated in in-depth interviews. Although the overall study identified several factors which permitted greater and lesser degrees of family involvement, this paper reports on one: the symbolic meaning shared by members about lay participation in their shared perspectives about “wrong parents” and “right parents.” Furthermore, two alternate types of “right parents” identified a psychologized version of parents as consumers, and a civic vision of parents as partners.

Results from this study are applicable to a wide array of lay–professional partnerships. This study suggests that in order to foster lay–professional partnerships in policy initiatives, lay participants must possess additional, civic-based skills, beyond those needed in the service delivery arena. Furthermore, organizational and professional change may be required to address professional dominance. Within mental health, lack of acceptance of nationally touted recovery-based models is a significant barrier. Finally, sociological implications of developing a civic-based framework for lay–professional partnerships are discussed.

Introduction

Consumer participation in service delivery and policy implementation

As patient/consumer participation in health care has gained momentum (Church et al., 2002; Sabin & Daniels, 1999), medical sociologists are increasingly scrutinizing relationships between professional providers and community members in policy arenas, as well as in service delivery. Yet such participation is not a new strategy in healthcare, either in the United States or elsewhere. Community participation programs have operated in the U.S. since the 1950’s (Irvin & Stansbury, 2004) or even earlier (Roberts, 2004). Beginning in 1978, the World Health Organization identified community participation as a cornerstone for health promotion strategies for *Healthy People 2000* (Zakus & Lysack, 1998).

Within mental health, the (U.S.) Final Report of the New Freedom Commission on Mental Health urged that opportunities be generated to “involve consumers and families fully in orienting the mental health system toward recovery” in planning, evaluation, and service delivery (New Freedom Commission on Mental Health, 2003, p. 37). Subsequently, greater scrutiny has been paid to family involvement in children’s mental health (Huang et al., 2005). As this paper discusses, however, the focus on recovery has not always existed (despite the international proliferation of recovery-based models in mental health policy and practice that emanated from consumer-led efforts challenging models of mental illness as life-long conditions).

Calls for greater consumer participation in policy efforts have not occurred in isolation. Organizations with different orientations and purposes implement these directives and, along with the mandate for consumer participation, they must meet other objectives. Therefore, while some prioritize consumer involvement,

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other groups identify goals which, at some level, are incompatible with lay participation.

This paper examines the experiences of three U.S. communities in implementing a service delivery framework for children's mental health, known as Community Collaboratives. Although the overall study identified several factors which permitted greater and lesser degrees of family involvement in the Collaboratives, this paper reports on one: the shared symbolic meaning held by members about lay participation in their shared perspectives about "wrong parents" and "right parents." While consumer-oriented perspectives about the "right parents" paralleled the extant literature on consumer involvement in service delivery, other findings suggest that lay members who participate in policy initiatives must possess additional civic-based orientations and skills. Themes about civic empowerment and recovery from mental illness emerged as particularly salient for lay involvement in mental health policy.

Background

Building upon early literature on the doctor–patient relationship (e.g. Parsons, 1951), medical sociologists and other health researchers continue to scrutinize how health and mental health providers interact with patients and their families in medical or therapeutic settings (Sabin & Daniels, 1999; Waitzkin, 2000). Frequently, family members have reported significant dissatisfaction with their children's providers (Knitzer, 1982; Leiter, 2004). Yet relationships with providers often are complex, as parents are dependent upon providers for expert care, while simultaneously advocating on behalf of their children and against the providers (Darling, 1988; Leiter, 2004). In turn, professionals often hold parents at least partially accountable for their child's condition and view them as more "needy" than they perceive themselves to be (Darling, Hager, Stockdale, & Heckert, 2002). Additionally, there are limits to the activities in which providers welcome parent involvement (Daneman, Macaluso, & Guzzetta, 2003).

Such complex and tenuous relationships in service delivery are likely to have ramifications for parent–provider relationships in policy settings. Yet scant attention has been paid to how health professionals view lay participation in implementing policy (Armstrong, Evans, & Wood, 2000; Briggs, Briggs, & Leary, 2006). This, however, has begun to shift as the policy climate has changed and moved toward mandating greater citizen participation.

Children's mental health and systems of care

In 1969, a report by the Joint Commission on the Mental Health of Children recognized the unmet need of children with mental health disorders in the U.S. Yet over a decade later in 1982, Janet Knitzer's seminal book *Unclaimed Children*, published by the Children's Defense Fund, documented that 3 million children had serious emotional disturbances and still were not receiving appropriate services. The book, in part, prompted the U.S. government to establish the Child and Adolescent Service System Program (CASSP) in 1983 which has since been renamed ("Comprehensive Community Mental Health Services for Children and Their Families Program") and brought under the aegis of the Substance Abuse and Mental Health Services Administration (SAMHSA). The primary focus of this federal program has been to develop community-based infrastructure for publicly-supported children's mental health services.

In 1986, Stroul and Friedman published their conceptualization of this "community-based system of care." Rather than being a model that could be replicated, Systems of Care were conceived as a framework for integrating services across many agencies treating children with Serious Emotional Disturbances (SED) who typically required supports in many parts of their lives. Continuing today, a single System of Care serves a demarcated geographical area (a single city or cluster of towns) and community-based providers from a range of service sectors (mental health, education, juvenile justice, etc.) work together to coordinate services within that geographical area.

While this early framework emphasized inter-agency collaboration as a way to expand community-based children's mental health services, subsequent restatements of the philosophy (Stroul & Friedman, 1986) identified family involvement and cultural competence as additional core values. This shift was due in part to the increasing visibility of the "family movement" in mental health as well as the 1986 Congressional mandate for family participation in state planning for community-based mental health. Thus, although focusing initially on inter-agency collaboration, Systems of Care quickly incorporated the simultaneous goal of being "family-focused." Professional and lay involvement, therefore, developed as separate but intertwined strands in this single framework. Continuing from 1994, one of the ten principles is that Systems of Care be "family focused" with family members being "full participants in **all aspects** of the planning and delivery of services" (Stroul & Friedman, emphasis added). Neither the framework, nor the legislation guiding the current state's implementation of the framework, however, has specified how this principle should be prioritized in tandem with the others. As this study demonstrates, that very ambiguity has significant repercussions for whether and how lay involvement is realized.

Nonetheless, Systems of Care have been widely adopted in the U.S. and have informed both private initiatives (through The Robert Wood Johnson and the Annie E. Casey foundations) and public efforts. "Healthy People 2010,"a federal initiative, prioritized Systems of Care, has promulgated their use as one of three treatment objectives in children's mental health. And federal Systems of Care grants have been awarded to over all 50 states, including 126 awards under the SAMHSA program (SAMHSA, 2008).

Community collaboratives

Today, many communities have incorporated three organizational subdivisions within the overarching System of Care. The Community Collaborative operates as a de facto policy planning board, open to public attendance and membership. In contrast, two closed groups coordinate services (Child Service Team) and provide executive leadership (Interagency Planning Team).

A few U.S. states have incorporated Systems of Care in their public programs. This study examines one state, a former recipient of CASSP funding, which recently used the Systems of Care model in its reform of publicly-supported children's mental health services. The state funded basic infrastructure services (such as care coordination) in several dozen communities and required family involvement in treatment planning and policy-making, most centrally through Community Collaboratives. The Collaboratives, therefore, became a central vehicle for incorporating parent participation.

Conceptual framework

The current study draws upon the concept of "shared perspectives" (Strauss, 1997) and uses a constructionist-structuralism framework informed by Bourdieu's "theory of practice" (1990), similar to that proposed by Hallett (2003) which synthesizes interaction, symbolic power, and an underlying negotiated order.

The concept of shared perspectives is used to examine whether and how Collaborative members believe that lay members should