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The Social Construction of Client Participation: The Evolution and Transformation of the Role of Service Recipients in Child Welfare and Mental Disabilities

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This article presents a comparative analysis of client participation (CP) in child welfare and mental health and mental retardation systems. It identifies three rationales for client participation (philosophical, pragmatic, and political), along with the limitations surrounding each rationale. It uses social construction theory to examine the historical and ideological underpinnings of organized, institutionally-sanctioned client involvement inside and outside government. In order to enhance the capacity of clients to influence service and benefit systems, their role must evolve through the mutual efforts of government—strengthening client participation policies and independent organizing from the bottom up through community development and advocacy programs.

Key words: *client participation, mental health system, mental retardation systems, social construction theory, child welfare, parent advocacy*

Background

Since the 1960s, active participation in the planning, implementation and evaluation by service recipients have been promoted (Arnstein, 1969; Friedman, 1977). Strong advocacy movements have shifted the perception of services from charity to the notion of rights and entitlements, including the promotion of recipients' voices and visions at the policy table (Fleischer & Zames, 2001). Moreover, privatization and other government accountability and efficiency efforts are encouraging the use of a market model with increased competition among providers and a limited role of government which facilitates consumer "choice" (Savas, 2000). Thus, the consumer "voice" and "choice" may be incorporated into expectations of social welfare programs from "above" through government mandates and performance indicators, and from "below" through service users and non-governmental entities (Aronson, 1993; Lammers & Happell, 2003; Mizrahi, 1992).

Yet, the notion of an active citizenry as the foundation for community development is often criticized for its limited inclusion of vulnerable and marginalized populations (Ghose, 2005). Efforts to coordinate and integrate service delivery are often unsustainable pilot–demonstration projects, or 'add on' programs without sufficient institutional supports or substantial change outcomes in programs and policies (Burford, 2005).

This article will present a comparative analysis of client participation (CP) in child welfare and mental health/mental retardation (jointly referred to as *mental disability*) systems. The child welfare and mental health and mental retardation systems were chosen as distinctive examples elucidating the scope and extent of socio-political forces that have influenced the development and current status of client participation with disenfranchised client populations. This article will identify philosophical, pragmatic, and political rationales for client participation, as well as highlight the limitations of CP. Social constructivism will serve as the theoretical lens from which to examine the historical and ideological underpinnings of organized, institutionally-sanctioned client involvement inside ("top down") and outside ("bottom up") government.

Definitions

There are differences in terminology for defining the topic here. Social workers have generally used the term *client,* although those who work in medical and psychiatric systems typically use *patient.* During the 1960s, the words patient and client in medical, mental health and social service systems were replaced with the term *consumer.* The term consumer implied more choice and autonomy by those receiving services (Mizrahi, 1999) and is still used by many agencies and recipients. As privatization of services increased, (Kahn & Minnich, 2005) a marketplace model reinforced the term *customer* within the not-for-profit and public sectors. The authors use *client* as the generic term, recognizing there are multitudes of meanings for service recipients. The authors refer to the mechanisms that establish client participation emanating from government as *top down/inside* and those emanating from non-governmental client and/or advocacy groups as *bottom up/outside.* The term *hybrid model* that integrates partnerships and/or collaborations between government and non-government entities is also used.

Social Construction Theory

The past and present social, political and economic contexts of the United States have served to shape how various constituencies within U.S. society construct the "lived out meaning" of clients (Danforth & Rhodes, 1997). An examination of client roles within the child welfare and mental disabilities systems assumes that the social designations of such client groups are informed by different ways of "knowing and seeing" (Bogdan & Taylor, 1989). Modes of knowing and seeing structured by social authorities (i.e. government, media and market economy) inform the content of client typologies. Collective knowing and seeing that has shaped the perspectives of the professional authorities and the social institutions in which they are engaged. This in turn shapes policies and practices regarding different groups of clients (Anderson, 1997). The response to the client voice is often subjected to a process of invasive labeling and hierarchal valuation derived from powerful social authorities who have assigned client culpability and client blame with reference to certain categories of service recipients (Blau, 2003). This phenomenon, also referred to as "the power over" paradigm, has been fostered by the medical, human service and legal systems (Forest, 2003). These in turn influence and interact with government policy and public perceptions from the media.

Within the child welfare system, the power over position, already sanctioned by government mandate and public perception, allows medical, legal and human service professionals to essentially become the social control agents of society (Madison, 2000). They have used a deviance model to criminalize the parent, moving beyond blame to punishment, which then shifts the characterization of the parent from victim to perpetrator (Conrad & Schneider, 1992). Criteria that focus on the client's capacity for market production and aggression have defined parents within the child welfare system as deviant from the "natural" relationship between child and parent (D'Cruz, 2004).

The "power over" paradigm with respect to the social construction of persons with mental disabilities also has been shaped by medical and psychiatric authorities with the sanction of government to involuntarily institutionalize and even incarcerate clients (Forest, 2003; D'Cruz, 2004). Medicine's and psychology's language of symptoms, diagnosis, compliance, and normalcy (the disease model) has been utilized to pathologize the problems of persons with mental disabilities. These models position professionals as experts and clients as passive recipients of 'treatment.' Hence, professionals authorized by government mandate (in the case of the severely and persistently mental ill) are the primary interpreters of clients' experiences.

Both the medicalization and criminalization of these two client groups at various points in history have served to separate clients from their personhood, family and community and even from society at large. Professionals are positioned as experts who not only define the problem, but have the authority to treat or contain it, often without the client's consent (Drake, 1992).

Rationales for Client Participation

The social construction of client groups has not only served to define how clients are perceived and treated, but has also informed various rationales for client participation (CP). Three distinct but overlapping rationales emanating from either or both the government, top down and/or the non-government, bottom up approaches are philosophical, pragmatic, and political.

Philosophical

Client participation is viewed as an essential part of a vibrant democracy. The United States government has prided itself in civilian rule and lay control, which over time has promoted the non-profit, voluntary health and human services sector apart from government and the marketplace. It is based on a belief in autonomous functioning and self-determining citizens. At the individual client level, CP increases self-esteem, self worth and self-efficacy of the client, identified in social work as "client empowerment" (Staples, 1992). It builds solidarity and cohesiveness among participants, and forms the basis of social networks also called "social capital" (Kirlin & Kirlin, 2002; Saegert, Thompson & Warren, 2001). At the macro level, an active citizenry can lead to stronger and more resilient communities (Fabricant & Fisher, 2002). Involved recipients of services have a greater stake in the social stability of their community; conversely, CP may lessen the estrangement among excluded segments of society. By establishing a constituency voice, CP has the potential to create a balanced form of trust, cooperation and synergistic relationships between government and community institutions, which can work toward a "common good" (El-Askari & Walton, 2005).

Pragmatic

From the perspective of service providers, CP is viewed as a financial and human resource investment that can also increase service utilization and effectiveness; programs work better when people are invested and have a sense of ownership. Feedback from client constituencies provides agencies and systems with a more accurate and realistic assessment of service and can lead to more innovative programs and processes (Dusenbury, Liner, & Vinson, 2000). Moreover, clients are an additional source of volunteer support, providing in-kind resources (i.e. goods, services, and staff) as well as direct financial contributions and investment. The term co-production has been used to denote input into professional service provision by clients and citizens (Gittell, Hoffacker, Rollins, Foster, & Hoffaker, 1980). Co-production links formal services to informal networks and mediating organizations, expanding the pool of assistance available, as well as creating more social capital (Saegert, Thompson & Warren, 2001). Empowered clients can move into para-professional staff and board leadership positions in traditional and alternative service delivery structures (e.g. mutual aid/self help groups; independent living centers). Hence, client involvement can hold dual leverage: reducing dependence on government funding and permitting a more independent voice for advocacy and social change (Abatena, 1997; Gamble & Weil, 1995; Hardina, 2003). If the practical basis for client participation is successful, these constituencies can also move into the political arena.

Political

An organized client base can build collective power by developing an invested, articulate and unified constituency. An active clientele from disempowered communities could lead to greater resources for that community, and/or more equitable distribution of resources and power. An engaged client community can have a direct influence on decision-making at the agency and ultimately on government when translated into voting power (Haynes & Mickelson, 2005). There may be greater willingness to trust in, support, and work with government collaboratively. Not only can CP develop individual leadership and spokespersons for issues and programs, but it can foster social consciousness and a collective identity with the potential for mass mobilization and movement building. Additionally, knowledgeable and organized client groups make it easier to hold government institutions accountable (Hardina & Malott, 1996). Conversely, from the government's position, CP can shift the obligation away from full and sole government responsibility to greater community and citizen responsibility for service provision.

Although there may be similar means for involving any client group or constituency inside or outside the system, there are historic and contemporary differences in how CP emerged between service sectors. Policy-makers and professionals who create and implement programs that impact these constituencies have an enormous effect on the extent and effectiveness of client input.

Limitations

The limitations of CP must be acknowledged. Most of the literature on the problems with client participation has focused on the more general concept of citizen participation; the voice of specific client groups has been given less attention (Arnstein, 1969; Gittell, Hoffacker, Rollins & Foster, 1980; Koneya, 1978). How various constituencies within society construct the "lived out meaning" of the client role derives from many social, political and economic factors (Danforth & Rhodes, 1997). Traditionally the onus of responsibility and blame is placed on the government and professional social construction of particular client groups and communities (Hardina & Malott, 1996). Given cultural divisions as well as ideological, class, race, and gender distrust within many communities, it has been difficult to give voice to client groups that have experienced political and economic discrimination. While marginalized and vulnerable clients may be the hardest to engage in CP processes, they are often the targets of government intervention and have the most at stake (Hardina, 2003; Abatena, 1997; Raco, 2000).

A combination of changing contexts, social conditions, and competent leadership inside and outside government, has shifted the social construction of CP in the child welfare and mental disability systems, although significantly more in the latter system. The historic and current top down and bottom up policies are presented next for each system. Although these are separated for analytical purposes, the inside and outside processes have been interactive over time.

Child Welfare System

Historical Context

Top down. Historically, the focus of the child welfare system has been on child "protection" from the natural/biological parent, rather than family preservation or reunification (McPhatter & Ganaway, 2003). *Parent* has usually been defined as the foster or adoptive parent. Federal regulations mandating natural parent participation beyond case planning do not exist. The absence of federal guidelines and mandates for parent participation in child foster care was seen as one result of the failure to create a singular bureau or to develop a coordinated federal response to the needs of children and families (Grason & Guyer, 1995). Instead, the federal foster care program is a mechanism for fund disbursement to the states which maintains regulatory responsibility and compliance with standards of eligibility for reimbursement of foster care costs. For years, parent participation was limited to those Federal child foster care regulations that dealt extensively with parental rights (Code of Federal Regulations, 2004) and the processes and requirements for state action in child removal, case planning, and to a lesser degree, family reunification.

At the state and local levels, the child welfare system has been plagued with scandals around issues of competency and resources (Jones, 2005). When a rare instance of extreme child abuse or neglect is highlighted in the media, it reinforces the social construction of all parents, especially parents of color and low income parents as culprits. Additionally, contracted arrangements between the state and local government and non-profit agencies to provide a wide range of services to families and children have traditionally favored child removal rather than maintaining children in their homes or with extended family members. This can be seen by examining regulatory compliance measures and monetary incentives (Hess, Folaraon & Jefferson, 1992; McPhatter & Ganaway, 2003).

The Adoption and Safe Families Act of 1997 (ASFA) [P. L. 105-89], along with the "Adoption 2002" initiative of the Clinton Administration, sought to reduce lengthy placements within the child welfare system. It attempted to clarify "reasonable efforts" requirements and relatives' rights to facilitate and encourage adoption of younger children and children with special needs through adoption incentives (Hollingsworth, 2000). For example ASFA provides financial incentives to states to increase adoptions, and the Small Business Job Protection Act of 1996 provides tax credits to adoptive parents (Hollingsworth, 2000), once again reinforcing child removal and termination of parental rights over prevention and family reunification.

Undergirding these systemic factors has been a "blame/ punish the victim" philosophy that has undermined the inclusion of natural parents' voices (Akinyela, 1997) since they have been viewed as the problem rather than as part of the solution. Under ASFA, Family Preservation Services provide time limited rehabilitation services of only 15 months duration for particular diagnoses or disabling conditions, reinforcing an approach that faults the parent for personal deficiencies and limitations (Hollingsworth, 2000). Not surprisingly, parental rights are increasingly being questioned (Montague, 2000), with some suggesting the privilege of parenting should be regulated through licensing requirements and standards (Dwyer, 1997). The blaming of persons of color is the lived experience, since a disproportionate percentage of African American and Latino children are in the system. Indeed, it has been labeled as "racist" by many critics (Fluke, Ying-Ying, Yuan & Patrick, 2003; Lu, Landsverk, Ellis-Macleod, Newton, Ganger, & Johnson, 2004). Moreover, intertwined with issues of race, a growing a growing body of literature indicates that "poverty is the single best predictor of child neglect" (Johnson, 1997 [in Hollingsworth, 2000]).

Bottom up. Historically, there have been very few organized attempts by natural parents to present an alternative view—namely that they are a disenfranchised population needing support and services, not demonization. Lawyers outside government have been among the few parent allies. Therefore, these advocacy efforts have mainly resided in the legal arena to gain rights for natural parents, and at the case level, to mandate and then enforce parental involvement in their own case planning. The failure to engage parents has been well publicized and documented. High profile court cases such as Nicholson, Wilder and Marisol cases in New York City (NYC) have propelled the right of parental voices onto the public stage (Bernstein, 2002). A review of parent participation literature revealed no grassroots, independent organizations that have addressed this omission prior to the 1990s, and only a few contracted agencies that offered parent support groups (Mizrahi, 2004).

Current Trends

Top down. Conflicting messages persist today; policies of prevention, family preservation and reunification are articulated in the same instance as are requirements for quicker adoptions, permanency planning and termination of parental rights. Nevertheless, there is a new focus on standards, competency, training and information systems to make the child welfare systems more accountable. In the last decade, the changes in the attitude toward and the treatment of birth parents is in part related to the acknowledgment that most of the cases that enter the system are for neglect rather than abuse (U.S. Department of Health and Human Services, 2005). This has accompanied the attendant recognition that a combination of drug abuse, poverty, domestic violence, welfare reform (which coerces mothers to work), discrimination and lack of child care, all have had immense adverse impact on parents' ability to keep families safe and intact (Halpern, 1999).

Furthermore, the ASFA recognizes that this stigmatized population of biological parents has not been adequately included as partners and problem-solvers. With the passage of ASFA and related federal child protection laws, the Federal government has included the term "consumer" in its standards for groupings which should be included in State agency planning and consultation. It has also mandated Citizen Review Panels to evaluate the extent to which states and localities carry out their child protection functions (The Family Violence Education and Research Center, 2004). These panels must include members "broadly representative of the community," although rarely are biological parents chosen to participate as citizens.

Bottom up. A growing bottom up advocacy and grassroots movement in the non-profit community has begun to shift the paradigm from child removals to more community-based solutions including the direct involvement of parents in decisions that affect their lives. One private foundation, the Child Welfare Fund (CWF) [www.nycwf.org], has had a profound impact on promoting parental involvement, youth participation (for those who have been in foster care, residential care, and group homes) and other systemic legal, social and political reforms.

A bottom up pioneer in parent participation is the Child Welfare Organizing Project (CWOP) [www.cwop.org]. CWOP organizes birth parents, trains parent advocates, promotes parent rights, and encourages agencies to place parents in board and staff positions. CWOP has also successfully advocated for mandated parent participation in government regulatory compliance mechanisms such as citizen review boards and case conference teams. In the last few years, as a result, in part, of outside activity by CWOP and other grass roots initiatives, the NYC Commissioner of the Administration for Children's Services (ACS) created a Parent Advisory Council which meets regularly with him. Moreover, local legislation was passed in 2005 at the NYC City Council (NYCCC) that requires non-profit child welfare agencies that contract with the city to hire parent advocates. The NYCCC has also created a city-wide Parent Advocate Advisory Council by law (NYC City Council, 2005).

Hybrid/mixed community-based collaborative models have also been established in the late 1990s in some states and large cities (Phillips, Gregory, & Nelson, 2003). These partnerships among government, service providers and civic and faith-based organizations are being established in targeted geographic communities with high rates of children-at-risk. The model attempts to bring to the table all the stakeholders who are involved with children and families, including parents, extended families ("kin") and neighborhood residents (Mulroy, Nelson & Gour, 2005). These neighborhood-based strategies often involve partnerships between the public and private sector. As of 2001, at least thirteen states had developed community-centered initiatives with collaborations as a central component (Walter R. McDonald & Associates, Inc., 2001). In NYC, ACS's paradigm has shifted to include a Department of Neighborhood Based Services and the establishment of community-based collaborations known as Neighborhood Networks (White, Rosenbaum, Lerner, & Nyary, 2005). Since 2006, larger Community Partnership Initiatives grants have been made available to encourage coordinated efforts of child welfare agencies, other community-based institutions and consumers (parents) [www.nyc.gov/acs].

These top down, bottom up strategies and hybrid structures are interactive and cumulative. Although growing slowly, the trend is clear; birth parents are beginning to be treated as partners with their collective voice and vision "at the table."

Mental Disability Systems

Contrast the struggle for parent/client participation in the child welfare system with the participation of persons with mental disabilities. Participation of people with mental disabilities in the establishment of their rights, protections and services is a well developed area in the U.S. despite the stigma of mental illness and mental retardation (Pederson, Chaikin, Campbell, & Arcand, 1993; Russ, 2004). This is evident in both the law and in agency policies and practices. The history of CP in mental disability is one of an extended interchange between top down and bottom up efforts, which demonstrate the power and value of organized consumer participation in spite of the negative social construction of clients as deviant, dangerous and/or incompetent. Advocacy models of participation are not limited to involving consumers of services, but include hybrid coalitions of families, social service professionals, and other advocates who work on behalf of their interests.

Historical Context

Top down. Historically, services for people with mental disabilities were the result of local and state mandates. Responses by the federal government to provide more humane institutional care in the 19th and early 20th centuries were the results of advocacy efforts and the Mental Hygiene Movement (Fellin, 1996; Mechanic, 1989). Similar to the historical construction of parents involved in the child welfare system, criminalization and medicalization were also utilized against persons with mental disabilities. For example, the ascendancy of the Eugenics Movement and the medical treatment model reinforced paternalistic state level approaches. Persons with mental disabilities were characterized as prone to criminality and promiscuity often as the result of in-breeding or genetic defects. Perceived as a threat to society at large and a burden to taxpayers, many states used institutionalization and compulsory sterilization of "defectives" (Wehmeyer, 2003). State governments maintained primary responsibility for coordinating and funding services that remained fragmented, with a preference for institutional care (Mechanic, 1989). Not until 1946, with the passage of the National Mental Health Act (P. L. 79-487), did the federal government bring the needs of one of these constituencies into sight. During this time frame, there was continuing isolation and stigmatization of the population while the medical treatment model gave control to physicians and other professionals who were assumed to make decisions "in the patients' best interest" (Fellin, 1996).

By the 1960s, two strong ideological streams contributed to a change in the social construction of individuals with mental disabilities. From the academic stream, the well known works of the sociologists Erving Goffman (*Asylums,* 1961) and Thomas Szasz (*The Myth of Mental Illness,* 1960) questioned the therapeutic value of large institutions and characterized custodial care as not very different from imprisonment. Moreover, the Joint Commission on Mental Illness and Health, established by the Mental Health Study Act of 1955, argued for the establishment of community mental health clinics and rehabilitation programs and expanded professional training programs outside institutions (Mechanic, 1989). The Joint Commission's report held sway with President Kennedy whose mentally retarded sister was housed in an institution at that time (Mechanic, 1989). Subsequently, the passage of the Mental Retardation Construction Act/Community Mental Health Centers Act (1963 PL-88-164) provided the funds to create independent non-profit health and mental health facilities, and mandated consumer participation on boards and in other facets of agency functioning.

In 1973, the Federal government passed the Rehabilitation Act which prohibited the discrimination against people with disabilities and included a requirement for a nationwide network of mandated, legally based disability rights agencies (www.ndrn.org) as well as federally funded programs of "protection and advocacy" for patients who remained in full time care (Title I, Part B, Sec. 112; 29 U.S.C. §§732). Also, in 1975, the Developmental Disabilities Assistance and Bill of Rights Act (PL94-103) was passed, which mandated every state to establish top down Developmental Disabilities Planning Councils and Boards of Visitors for residential care facilities to oversee the care given. In addition, residential treatment programs established Mental Health Advisory Councils which specifically required consumers and family members to participate in oversight of those facilities (*Mental Hygiene Law, Laws of New York* [1977], Ch. 978).

However, with the election of Ronald Reagan, a conservative counter-trend catapulted onto the political landscape. In 1980, the Mental Health Systems Act began the disengagement of federal funding (New York State Office of Mental Health, 1981), while the passage of the Omnibus Budget Reconciliation Act of 1981 further dismantled the system, devolving it to state and local responsibility through block grants. More ominously, the Reagan administration began to espouse a conservative moral and fiscal agenda which entailed a social construction of the poor, the homeless and the mentally ill as defective, dangerous or morally deficient. Even providers and advocates who spoke on their behalf diminished the voice of clients and treated them as victims rather than resources or partners in care (Bogard; 2001; Wagner & Cohen, 1991). This maintains clients in a subordinate role, perpetuating the reality of "disability ghettoes" (Rose-Ackerman, 1982; National Coalition on Disability, 2000).

Nevertheless, during the Reagan-Bush years, most of the laws and regulations passed in the prior decades continued to be implemented to varying degrees at state and local levels. This appears to be due to a combination of grassroots bottom up activism, and creative top down models at the administrative levels of government (Fleischer & Zames, 2001; Linhorst, Eckert, & Hamilton, 2005; Miller & Keys, 1996). The social construction of disability had shifted so fundamentally that the empowerment of people with mental disabilities could not be totally reversed.

Bottom up. There has been a significant history of bottom up parent involvement in the development of rights and services for their mentally retarded children outside government in the U.S. beginning as early as the 1930s and 40s, and coming of age in the 1950s (Goode, 1998). Furthermore, the community mental health movement, advocating for closure of large public state hospitals and a shift in resources to community-based services, especially for the poor, vulnerable and marginalized populations, gained considerable power after World War II. These advocacy efforts were able to establish a range of institutional and community-based educational and support services in the non-profit sector, including the long-standing organization, ARC (www.thearc.org) [formally known as The Association for Retarded Children]. This group of mostly middle class parents fought for and developed a range of separate services for their offspring, first as children and then as adults, with minimal assistance of professionals. Ultimately their efforts took hold with some success in integrating educational, social and rehabilitative services into the mainstream service system (Rose-Ackerman, 1982). Nevertheless, even with this activism and the introduction of medications in the 1950s, government and professional authorities continued to promote a social construction of those with mental disability as a population who needed isolation and protection from society, and a society that needed protection from them.

While John F. Kennedy's authority as President mobilized legislators and policy-makers, his legitimacy as a family advocate galvanized the disability rights movement. By 1967, parent and professional advocates issued a declaration of rights for the mentally retarded since the law continued to deny them legal status and viewed them as non-persons (Cross, 1971). The civil rights movement, with its emphasis on social inclusion, expanded the notion of civil liberties and civil rights to the mental disability system. Mental health consumers also came out of the institutions and strategically attempted to shift the social construction of their condition by labeling themselves as survivors and inmates (Campbell, 1992).

During the early 1970s, parents and clients with physical and mental disabilities began to collectively organize at the grassroots level. The independent living movement rooted in self-determination and consumer direction (National Coalition on Disability) [NCD, 2000], advocated for access to a range of services, as well as rights and protections beyond the health and mental health systems (Fleischer & Zames, 2001). This included "the right to refuse treatment" and "the right to treatment" in mental hospitals (Mizrahi, 1992). As with the larger civil rights movement, the disability rights movement gained momentum as civil lawsuits brought on behalf of the mentally disabled assured they were seen as persons with rights protected under law (Cross, 1971). Of note, the landmark case *Wyatt v. Stickney* was filed, recognizing the due process rights of the mentally ill and mentally retarded (325 F. Supp. 781, 784) [M.D.Ala.1971] and, by 1972, a consent agreement (344 F. Supp. 373, 378-86) [M.D.Ala.1972], established minimum standards to meet due process rights (Mechanic, 1989). Also in 1972, the Association for Retarded Children, along with other organizations, brought a class action lawsuit against the State of New York on behalf of patients in the Willowbrook State School (Unforgotten, 1997). Pressured by media exposés of horrendous conditions in state institutions such as Willowbrook (Jurkowski, Jovanovic & Rowitz, 2002), many other states began the process of deinstitutionalization of their facilities and established a continuum of community-based services (Segal, 2008). The independent living and normalization movements, along with the National Alliance for the Mentally Ill, emerged at this time and continued to advocate for additional laws and funding for services, research and community participation in health and mental health planning to expand the rights of people with chronic diseases and disabilities (Kopolow, 1981).

Current Trends

Top down. It was grassroots, bottom up movements of client and advocacy groups that promoted the passage of major pieces of legislation requiring an active role for those affected by disabilities (El-Askari & Walton, 2005; Fleischer & Zames, 2001; Parker, Mangolis, Frag, & Roldo, 2003; Russ, 2004). Passage of the American with Disabilities Act of 1990 (42 U.S.C. §§ 12101), prohibiting discrimination of individuals with or perceived as having physical and/or mental impairments, was a product of persistent claims for equality in spite of the ideology of the presidential administration of the time. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 reaffirmed the Protection & Advocacy (P&A) system (http://www.acf.hhs.gov/programs/add/states/pnafactsheet.html) and assured that the voices of individuals with disabilities would be heard.

Bottom up. In the 1990s, the "self advocacy movement" blossomed outside government with individuals with mental or developmental disabilities serving as their own spokespersons (Miller & Keys, 1996; Stroman, 2003). Collective advocacy programs have developed training programs for individuals with disabilities to strengthen the consumer participatory system (Stringfellow & Muscari, 2003). Mental health consumers also continue to preserve their autonomy and rights to services in spite of cutbacks and a more restrictive definition of disability since 2000. Ironically, the conservative notions of consumer choice and self-reliance are aligned with the principles of the independent living movement, which encourages individuals to "take increasing control and responsibility for our recovery and lives..." (Fisher, 1994, p. 914). These values of self-determination and holistic choices, among others, unite liberal consumer and more radical survivor organizations (Mental Health Consumer/Survivors Create National Coalition, 2007).

Hybrid models of collaboration have emerged where professional service providers and advocates are allying with clients to build more unified movements (Farley, 1995). Continued advocacy and a cross-disability approach to disabilities are important in diminishing divisiveness among disability communities (NCD, 2000). There are continuing attempts to form multi-disability coalitions to gain a stronger political voice and increase visibility of all people with disabilities at the policy tables (Charlton, 2000). For example, in 2006, the Mental Health Consumer/Survivors Create National Coalition, a national coalition of organizations run by consumers, including representatives of federally funded consumer run programs, was launched (www.ncmhcso.org). The power of hybrid approaches is reflected in the signing of the United Nations Convention on the Rights of Persons with Disabilities in December 2006, by almost half of the member nations (www.un.org).

Discussion

The interaction of the aforementioned top down and bottom up strategies has transformed the social construction of these two stigmatized and disenfranchised constituencies. Rather than being perceived as solely passive recipients of service, they have become active participants and needed contributors to society's functioning. Nevertheless, there are different social and historical factors affecting the way natural parents in the child welfare system and people with mental disabilities have been perceived and have acted historically.

For clients with mental health and developmental disabilities, a combination of grassroots, public advocacy, popular education, and local services helped to connect their needs to larger, more broadly based movements. These also helped shape a federal role in defining the rights and protection of individuals with disabilities. As the Federal government mandated client as well as family inclusion, more consumers had opportunities to become leaders and spokespeople. Indeed, they have been able to impact the creation of outcomes indicators and serve as part of evaluation and assessment teams (Campbell, 1997). Nevertheless, parity between physical and mental disabilities with respect to services and spokespeople has not yet been achieved.

For parents in the child welfare system, authorities within the Federal government have remained largely silent regarding the inclusion of their voices beyond statutory case planning. Indeed, the tendency remains, albeit to a lesser degree, to blame parents for victimizing their children rather than seeing them as citizens struggling against poverty and oppression, who, with support, can become resources for family problem-solving and community building. Nevertheless, the emergence of child welfare advocacy groups from the voluntary sector suggests individuals are mobilizing even if these efforts are not consistent from place to place. The child welfare consumer participation efforts are in their infancy and need to be supported, guided and consolidated if parents are to have a legitimatized and meaningful voice. Mandates for citizen participation must be accompanied by technical assistance and financial supports (Dusenbury, Liner, & Vinson, 2000). If government and professional authorities can support parental experience as a variable and indicator of outcomes, the increased privatization and outcomes focus of child welfare may offer an opportunity to create the processes and structures necessary for systematic consumer input (Alpert, 2005). De-stigmatizing the involvement of families and parents is vital in order to address issues of public policy, organizational culture, professional discriminatory attitudes and client alienation that prevent the mass mobilization of vulnerable parents working toward true social inclusion (Burford, 2005).

There is a need for both inside/top down and outside/bottom up strategies to co-exist. Without government authorities who implement and enforce the right of people to participate, it is difficult to have a significant impact on benefits and services. By itself, however, there are limitations to a mandated top-down model that creates government mechanisms to incorporate citizens into organizational and political life. Experience demonstrates that many client groups are critical of government which they see as supporting their participation in superficial, tokenistic ways (Gittell et al., 1980). Client disillusionment and co-optation can lead to disappointment and distrust (Hardina, 2003; Koneya, 1978), furthering the government's limitations in engaging and sustaining participation, especially from a diverse group of clients and staff (El-Askari & Walton, 2005). Client groups organized by and for clients are essential in countering governmental pressures to construct a uniform client perspective in public policy that minimizes legitimate participation.

Clearly, there are different meanings and rationales for client participation. For example, Gramsci (1971) explicates how the interpretive power of social authorities can limit and inform client participation among disenfranchised client populations, "by shaping perceptions, cognitions and preferences ... clients accept their role in the existing order of things because they can see or imagine no alternative" (in Lukes, 1974, p. 24). For professional authority to be deployed constructively rather than oppressively, the integration and awareness of socially constructed client and professional identities is essential. Such knowledge will assist in facilitating client participation that avoids tokenism and provides opportunity for mutual dialogue, critical reflection and negotiation (Arnstein, 1969; D'Cruz, 2004). Therefore, it is important that professional staff convey the need to balance expectations and reality with respect to level and scope of decision-making. There is a need to recognize and address the inevitable tensions between what clients might demand (client control and full self-determination) and what a government or an agency might be prepared to offer (a seat at the table and one of multiple voices) [Advisory Commission on Intergovernmental Relations (ACIR), 1980]. There is a danger of building clients' false hopes regarding systemic changes and policy outcomes on one hand, and on the other, of fostering too low expectations on the part of government officials and agency administrations about the impact of involving clients. Addressing constraints and potential trade-offs with official stakeholders and clients is an important role for those professionally trained in community organizing, planning and development (Gamble & Weil, 1995; Weil & Gamble, 2005). Continued well-funded evaluations of these efforts is also essential

Neither clients nor the government are monolithic entities. There are as many differences within each cohort as there are between them. The challenge for both groups is to define and seek the "common good" and the "public interest," and to balance the views of all affected interests (ACIR, 1980; Kirlin & Kirlin, 2002). True inclusion of these divergent interests and voices requires recognition of differential power and status between clients and those holding authority in order to minimize this power differential where possible (Drake, 1992; Raco, 2000).

Conclusion

This article has attempted to document how the social construction of the role of the client shapes the policies of client participation both inside and outside the system. In order to enhance the capacity of clients to influence service and benefit systems, their role must evolve through the mutual efforts of government strengthening client participation policies and independent organizing from the bottom up through community development and advocacy programs (Koneya, 1978;

Littell & Taylor, 2000; Linhorst & Eckert, 2003). There must be an acceptance that both consensus and conflict strategies used by clients and government are inevitable, even necessary (Hardina, 2003). There must also be a recognition that voluntarism (bottom up) and formal institutionalization (top down) are not mutually exclusive. The term "institutionalized voluntarism" (Nanetti, 1980) has been used to acknowledge the need for structure and for open, inclusive and effective processes. In order to realize the philosophical, pragmatic and political aspects of client participation, and to minimize the limitations, all players must accept the importance of those ends and be willing to implement a range of means and methods for achieving them.

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