Development of a Model for the Implementation and Evaluation of Citizen-User

Involvement in Mental Health Policymaking: A Case Study

by

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Abstract

The purpose of this research was to develop a model for the implementation and evaluation of citizen-user involvement in mental health policymaking. The study explored the pathways through which the experiential knowledge of citizen-users enters policy processes, how the outcomes of citizen-user involvement are conceptualized by policy actors, and the contextual factors that influence the implementation and outcomes of involvement.

Qualitative instrumental case study methodology was used to focus on the policy field of mental health and social housing. Data were collected through key informant interviews with a purposive sample of 21 people recruited from four policy actor groups: citizen-users, representatives of advocacy organizations, government officials (elected representatives and bureaucrats), and service providers. A review of policy documents as well as forum, committee and task force reports provided additional data for the study.

The research built on a previous study that developed a model of the important processes that are used to engage citizen-users in decisions about services and policies. Findings from the current study built on this model by exploring the outcomes, pathways and contexts of involvement from the perspectives of policy actors. Four categories of outcomes were identified: substantive, instrumental, normative and personal. Benefits and risks of involvement were identified within each category. Participants described direct and indirect pathways through which the voices of citizen-users have gained access to policymaking. Direct pathways were those through which individual and collective voices of citizen-users have communicated directly with decision makers. Indirect pathways represented the ways in which the voices of citizen-users were mediated by

other policy actors. The findings also highlighted five contextual factors that have influenced citizen-user involvement: the socio-political environments, institutional characteristics, participant characteristics, opportunities to be involved and other influences on policymaking.

This research has added to knowledge about the important components of citizen-user involvement in policymaking. The results provide guidance to policy actors about ways to enhance involvement. People with mental health and social housing needs have important experiential and other knowledge to contribute to policymaking. The challenge is the ongoing search for the means to ensure that their voices are heard and carry weight.

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Chapter 1: Introduction

The involvement of people who use mental health services in policy decisions has become increasingly important in recent years. Mental health consumer and professional groups have articulated the need for an increased role of service users in planning, implementing and evaluating mental health services (Canadian Alliance on Mental Illness and Mental Health, 2003; Canadian Collaborative Mental Health Initiative, 2006). Through the Social Union Framework Agreement (SUFA), governments in Canada have made commitments to increase involvement of citizens in health and social service policymaking (Government of Canada, 1999). Recommendations have been made to the Ministries of Health in Canada to include performance indicators related to the inclusion of persons who use and who may benefit from mental health services in their accountability frameworks (McEwan & Goldner, 2001). Specific commitments have also been made by the provincial government in Manitoba through requirements that Regional Health Authorities include people who use mental health services (Manitoba Health, 2003) and their families (Manitoba Health, 2005) in decisions about the planning, implementation and evaluation of services. Despite the support for involvement by governments and interest groups, the development and evaluation of public participation practices is poorly understood in the health sector (Abelson & Eyles, 2004; Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006).

This thesis explored the involvement of people who need and use mental health services in the development of public policy. Qualitative case study methodology focused on the policy area of mental health and social housing. This policy area was chosen as an illustrative example of how involvement can unfold around a policy issue to formulate a

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model that can be applied to the implementation and evaluation of involvement. The development and validation of this type of model can have multiple applications. The model can be a catalyst for discourse and debate about concepts and principles of involvement, thus raising awareness of common understandings and differences. The model can elucidate the ideal processes, outcomes and contexts that will promote the meaningful involvement of people who need and use mental health services in mental health policymaking. In this way the model can become a guidepost for the development of involvement processes and promotion of opportunities for meaningful engagement. Finally, the model can clarify criteria for the evaluation of involvement processes to promote accountability to citizen-users and citizens at large.

Terminology

This thesis will explore the involvement of people who need and use mental health and housing services in policymaking related to mental health and social housing. Terms used to describe people who use mental health services, the involvement of people in policymaking, and issues related to social housing are inconsistent in the current literature. Different terms have been used interchangeably and similar terms have been used to mean different things. This section will outline key terms and definitions as they will be used in this thesis and provide an overview of current understanding of the concepts.

Citizen-users

Many terms have been used to describe people with mental health problems who access the mental health system. These terms include patient, consumer and client.

Recently, increased emphasis has been placed on taking a citizenship approach to constructions of people who use mental health services. For the purpose of this thesis the term *citizen-user* will be used to refer to people who currently use, or are eligible to use, both mental health and housing services.

Historically, the term consumer gained acceptance as a term of empowerment over the passivity that was inferred in the term patient. Consumerism became an important principle within the disability rights movements of the 1970s. Consumerism asserted that people with disabilities were in the best position to know what they wanted and needed and should have a say in what services they were offered (DeJong, 1979). The neo-liberal market driven approaches predominant in the 1980's and 1990's emphasized a consumerist approach to involvement of users in health services by emphasizing access to information and choice of services (Cawston & Barbour, 2003; Coney et al., 2004). However, even as far back as two decades ago Chamberlin (1990) criticized the term and the approach because power differentials between those who delivered and those who received services continued to exist but the approach served to downplay the more radical voices in the ex-patient movement. More recently, the consumerist view of choice has been under scrutiny because it implies that individuals have access to sufficient information and influence over the managerial decisions that drive the types of options from which to make choices (Barnes & Prior, 1995; Vidler & Clarke, 2005). Particularly in relation to mental health service, choice decisions may be difficult or impossible to make due to the common symptoms of mental illness which may reduce individuals' abilities to consider, weigh and choose options (Barnes & Prior, 1995) and because often treatment is imposed (Barnes & Prior, 1995; Chamberlin, 1990).

Although the principles of self-determination and choice continue to be valued (Cook & Jonikas, 2002), increased emphasis has been placed on taking a citizenship, rather than consumerist, approach to constructions of people who use mental health services. Understanding people who use services as citizens places more emphasis on facilitating peoples' opportunities to become social actors who can have a holistic influence on society and health policy (Cawston & Barbour, 2003; Saltman, 1994). For people with psychiatric disabilities, taking a citizenship perspective can promote efforts to change the power relationships that contribute to their position of disadvantage in society (Clark and Krupa, 2002).

The term citizen refers to a formal relationship between a person and the state. In Canada citizenship confers both rights and responsibilities. The Canadian Charter of Rights and Freedoms (Government of Canada, 1982) identifies multiple rights including, but not limited to:

1. Democratic rights (to vote for and become members of the House of Commons)

2. Fundamental freedoms (for example of thought, opinion, expression and association)

3. Legal rights to life, liberty and security

4. Equity rights

Concurrent with these rights is the explicit expectation that citizens will also assume responsibility to obey laws, respect the rights and freedoms of others, and vote in elections (Government of Canada, 2006). Beyond the right to vote for representatives, and the expectation that citizens will exercise that right, lie more implicit issues of social

justice. In this regard, Young (1990) argued that a requisite of social justice is that "each person should have the institutionalized means to participate effectively in the decisions that affect her or his action and the conditions of that action" (p. 251).

Despite the appeal of the word citizen to emphasize the positioning of people within a society as individuals with rights and responsibilities, the term is not without problems. The primary problem is that citizenship is exclusionary. If Young's (1990) position that social justice is about all people impacted by a policy having a say in decisions about the policy then the use of the term citizenship may technically exclude those people who are newcomers to a country, visitors, or are impacted because of the policy's transnational influence. The term citizen also has some implications related to people for whom some, or all, of their citizenship rights have been suspended such as those who are incarcerated in penitentiaries or who have been committed involuntarily to mental health facilities. These positions within society have implications for people's opportunities for involvement in public policy discourse and decision making.

Another caution about the use of the term citizen is that, as participants in public policy decision making, citizens' positions and opinions can be constructed by others as representative of a more general public opinion. Participants assume positions and perspectives within participatory process which may change over time (Kerr, 2004; Lomas, 1997). For example, a participant may be a citizen who pays taxes, a user of services, and a service provider (Lomas, 1997). These multiple positions and the fluidity among positions need to be recognized regardless of the terminology used.

Despite its limitations, the term *citizen* will be used in this thesis to emphasize peoples' opportunities to become social actors who can influence social and health policy (Cawston & Barbour, 2003; Saltman, 1994). This idea of a citizen is in keeping with Lister's (2003) conceptualization of citizenship, as "a status, carrying a wide range of rights, and as a practice, involving political participation, broadly defined" (p. 42). "Broadly defined" political participation includes diverse possibilities for participation in both formal and informal collective political activities.

The inclusion of the term *user* is defined broadly to include people who currently use mental health services, those who may have used services in the recent past and those who need services but don't use them. For the purposes of this thesis citizen-users are defined as people who use or need mental health services and social housing and who have rights and responsibilities as social actors in policymaking.

Citizen-user Involvement

Citizen-user involvement will be used to describe all the ways that citizen-users can be "actively involved in understanding, assessing or resolving issues of public concern" (Health Canada, 2000, p. 26). Involvement can be conceptualized on a continuum in relation to the amount of influence citizens have in policy making. In general, typologies of level of involvement are thought to range from governments giving information to citizens to citizens having real decision making influence. The various perspectives on types of decision making involvement will be discussed in detail in Chapter 3.

Involvement mechanisms will refer to techniques, initiatives and forums that are intentionally organized by public bodies for the purpose of including citizens in discussion of issues of public concern. Examples of mechanisms are governing boards, advisory committees, focus groups, surveys and Citizens Juries. There is little consistency in the literature related to the nomenclature for these mechanisms. For example, Rowe & Frewer (2000) used the term "engagement mechanisms" in their typology, whereas Health Canada (2000) referred to "public involvement techniques" to mean essentially the same thing. For the purposes of the thesis the term "involvement mechanisms" will be used to be more consistent with Health Canada's use of the term "involvement". The term mechanism will be used to emphasize the characteristics of these activities as a means to an end. Mechanisms have been classified according to levels of involvement ranging from informing citizens, consulting with them or including them in decision making (e.g., Health Canada, 2000). Mechanisms can involve communication among a variety of people and groups with an interest in a policy issue including government, citizens, and interest groups, businesses and others (Renn, Webler, & Weidemann, 1995).

Homelessness and Housing

Currently, there is no consistent definition of homelessness (CIHI, 2007). People can be considered homeless when they are living on the streets or in abandoned structures not meant for habitation (*absolute homeless*). People who are homeless also sleep in emergency shelters. Some definitions of homelessness also include people who live temporarily with others such as family or friends (*hidden homeless*). People who spend

more than 50% of their income on housing are often considered to be at *risk of homelessness* (CIHI, 2007).

The Canada Mortgage and Housing Corporation (n.d.) has identified a basic standard of housing as being *adequate* in condition (not requiring major repairs), *suitable* in size (as determined by the number of bedrooms for the makeup of the family) and *affordable* (costs less than 30% of household income). If one or more of these standards are not met then the household is considered to be in *core housing need*.

There are several definitions related to type of housing. *Social housing* refers to housing that is publicly funded such as public, non-profit and co-operative housing (Canadian Mental Health Association (CMHA), 2004). Public funding can also be used to subsidize rents in private rental markets. *Transition housing* refers to housing arrangements such as transitional shelters that are occupied for short periods with supports for people transitioning from one living arrangement to another (Carter & Polevychok, 2004). *Custodial housing* requires operators to provide a standard of service to all tenants that include support for basic daily living needs like meals and laundry (Centre for Addiction and Mental Health (CAMH), 2002). *Supportive housing* has support services related to skill building linked to the housing unit. Tenants generally are viewed as program clients (CAMH, 2002). In contrast, *supported housing* has services that are not linked directly to the housing unit. Services tend to be individualized and can follow the person requiring support even if the person changes living arrangements (CMHA, 2004).

Policymaking

Policy, for the purposes of this thesis, will be defined as "a course of action or inaction chosen by public authorities to address a given problem or interrelated set of problems" (Pal, 1992, p. 2). Policymaking occurs in a series of five stages that create the process by which problem solving occurs through experimentation and learning (Howlett, Ramesh & Perl, 2009). Howlett and colleagues have described these stages as follows: agenda setting is the process by which problems are identified and recognized by government; policy formulation is the stage at which governments identify the options for solving the problem; decision making is the process by which governments choose a course of action or inaction; policy implementation is the stage at which governments put their policy choices into effect; policy evaluation is the process by which policies are monitored (p. 12). Howlett and colleagues acknowledge that these stages can provide a framework for understanding policy process but do not necessarily occur in a predefined or well-structured order.

Nonetheless, the policy cycle is important in relation to citizen-user involvement because it suggests the complexity of the policymaking process and highlights the places in which citizen-users may be included in, or excluded from, policy discourses. For example, opportunities for inclusion in discourse are likely to be available to almost anyone at the agenda setting and implementation stages, but only to a smaller network of policy actors at the policy formulation and implementation stages and open only to government at the decision making stage (Howlett et al., 2009). Policy actors' involvement in various stages of policymaking will be discussed in more detail in Chapter 2.

Structure of the Thesis

The thesis is divided into several chapters. It begins with a review of the literature related to mental health and housing policy in Chapter 2 and to the implementation and evaluation of the involvement of citizens and citizen-users in policy development in Chapter 3. This thesis has built on previous research on the implementation of citizen-user involvement in mental health service delivery. The previous work is summarized in Chapter 4 and publications arising from the previous research are included in the appendices. Chapter 5 describes the methodology used in the thesis research. The findings are reported in chapters 6 to 11. A manuscript approach has been used to report the findings of this research. Chapter 6 provides an introduction to the results. Chapters 7, 9 and 11 are written as manuscripts that have been submitted to peer-reviewed journals. The format of these chapters is consistent with the guidelines of the journals to which they were submitted and, therefore, nuances in formatting and referencing vary from each other and the manuscript as a whole. In addition, there will be some repetition with other chapters in the thesis including the literature review and the methods chapters. To preserve continuity between the manuscripts, chapters 8 and 10 serve as links between manuscripts. Chapter 12 provides reflections on the process of conducting the research and a discussion of the limitations of the research. Finally, Chapter 13 summarizes overall policy recommendations and directions for future research. References can be found at the end of each chapter.

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Chapter 2: Mental Health and Housing Policy

Housing as an Important Policy Issue for People Living with Mental Illness

The link between the need for good social housing policy and the challenges faced by people with severe and persistent mental illness have been well established (Canadian Institute for Health Information, (CIHI), 2007; Dunn, 2002; Standing Senate Committee on Social Affairs, Science and Technology (SSC), 2006). Housing has increasingly been conceptualized as both an important resource for people experiencing mental illness (Trainor, Pomeroy, & Pape, 2006) and as a social determinant of mental health and wellbeing (Dunn & Hayes, 2000; Hwang et al., 1999). People who experience mental illness frequently report concerns about difficulties accessing safe and affordable housing (SSC, 2006) and are often over represented in groups who are homeless (CIHI, 2007). Furthermore, poor housing conditions can negatively affect the health and well-being of people with mental illness (Dunn, 2002).

The importance of adequate and safe housing for people with mental illness has long been recognized (Federal/Provincial/Territorial Advisory Network on Mental Health, 1997) but recently has emerged more prominently on the public policy agenda. The Standing Senate Committee on Social Affairs, Science and Technology (2006) issued a strong recommendation for immediate action to address the issue of social housing for people experiencing mental illness. Taking action to address this policy issue is complex. This policy issue crosses hierarchical levels of policymaking in federal, provincial/territorial and municipal governments, as well as horizontal government departments and quasi-governmental structures (i.e., Regional Health Authorities and

Crown Corporations). If citizen-users are expected to be included in policy processes, how can their involvement be facilitated and evaluated within the complex web of negotiations, debates and deliberations that are inherent in policymaking?

An overview of delivery models for mental health services provides an historical context for current housing issues for people with mental illness. Early in the 20th century, many people with mental illness were housed in large institutions where they remained for many years, often for the remainder of their lives (Kirby & Keon, 2004). Following World War II, a process of deinstitutionalization became public policy encouraged by understaffing and overcrowding of psychiatric institutions, research suggesting the negative effects of institutionalization on health and well-being, and the advent of neuroleptic medication in the treatment of psychosis (Kirby & Keon, 2004). The process of deinstitutionalization reduced the number of psychiatric beds across Canada. For example, using Statistics Canada data, Sealy and Whitehead (2004) reported that the bed capacity of psychiatric institutions in Manitoba decreased by 68.6% from 1965 to 1981 to a total bed capacity in 1980-1981 of 1157. The way that deinstitutionalization unfolded in Canada resulted in closed psychiatric hospital beds, increased number of general hospital beds and insufficient funding to support the people who were discharged into the community. This situation resulted in people having frequent readmissions to hospital, increased homelessness and increased incarceration in the criminal justice system (Kirby & Keon, 2004, p. 141). During the 1970s and 1980s community based services were developed and many non-governmental organizations pressed the government to provide more community supports while professionals advocated for more treatment. Many people became housed in residential care facilities providing custodial support. During the 1990s

more emphasis was placed on providing integrated community supports (Kirby & Keon, 2004) that were flexible to meet the needs of individuals. Increasingly a greater emphasis was placed on encouraging models of supported and supportive rather than custodial housing (Winnipeg Regional Health Authority, 2003). Most recently, evidence is emerging that a *Housing First* model, in which establishing stable housing is a priority that is not contingent on treatment, can have a positive impact on the maintenance of independent housing for people living with mental illness (Tsemberis, Gulcur, & Nakae, 2004).

Accompanying the need for community housing and supports for people with mental health problems, other changes to housing policies have restricted access to affordable housing. During the 1990s the federal government substantially cut funding for low-cost, co-operative and new social housing (Canadian Mental Health Association, 2004). In 1996, responsibility for social housing was transferred from the federal government to the provinces through the Canada Health and Social Transfer (Mulligan, 2008). For many people with severe and persistent mental illness who live in poverty, access to affordable housing became more elusive.

Currently, the lack of affordable housing stock continues to disproportionately affect people with mental illness (Mulligan, 2008). Issues of homelessness, shelter allowances for people on employment and income assistance that are well below rental rates, large wait lists for subsidized housing, homelessness and housing discrimination continue to affect people with mental illness (Mulligan, 2008).

Despite acknowledgement of the need to address housing issues for this population (SSC, 2006; WRHA, 2003), several challenges are evident. First, both mental

health (Romanow, 2002) and housing (Carter & Polevychok, 2004) have been called "orphaned children" of public policy. Together they create an important, but largely neglected, area of public policy attention. Second, inter-departmental boundaries between health, housing, and other associated issues such income assistance, have resulted in a lack of clear leadership for addressing housing policy related to the needs of people with mental illness. Finally, despite a few examples in Canada of mental health service users being involved in reorganization of housing services (e.g., Lord, Ochocka, Czarny, & MacGillivary, 1998) there has been a relative lack of documentation of engagement and influence of people with mental illness in the development and implementation of public policy related to housing. Therefore, the needs, goals and choices of the people who would benefit, or suffer, most from mental health and housing policy have not been heard.

The relationship between housing and mental illness is complex. There has been considerable recognition that people who experience mental illness often have difficulty finding safe and affordable housing (SSC, 2006). Homelessness can be related to a variety of factors including poverty and housing availability (CIHI, 2007).

Several models of housing support for people with mental illness have been utilized. However, what people have experienced in housing arrangements and what they see as desirable are often very different (Forchuk, Nelson, & Hall, 2006). People who use mental health services express the desire for stability, affordability, privacy, safety, opportunities for social integration, and choice (Forchuk et al., 2006). All of these preferences are basic and common desires for housing but are seemly difficult to attain for many people with mental illness. Other research (Nelson, Sylvestre, Aubry, George,

& Trainor, 2007) has suggested that, for people living with severe mental illness, choice and control over housing and perceptions of higher quality housing are positively related to self-reported quality of life. Thus, both the availability housing options and choice over housing appear to be important to the well-being of people living with mental illness.

In addition, research is suggesting that housing is also a determinant of mental health and wellness. Issues such as building physical characteristics and housing density (Hwang et al., 1999), housing satisfaction (Dunn & Hayes, 2000; Hwang et al., 1999) and the amount of control people experience at home (Dunn & Hayes, 2000) may all impact on mental health. Housing insecurity is also being conceptualized as cause of social exclusion (Bradshaw, Kemp, Baldwin, & Rowe, 2004) which can impact indirectly on mental health and well-being. People who are homeless often report a variety of health conditions, concerns about safety and perceptions of social isolation (Daiski, 2007).

The relationship between mental health and housing is complex. So too, are the potential routes through which policy development and implementation can occur.

Policy Actors

To understand the impact that citizen-users can have in policy decision-making about social housing it is first important to understand the policy sub-system in which these decisions may be made. The model proposed by Howlett, Ramesh, and Perl (2009, p. 83-84) will be used to describe the institutions and actors that could influence policy discourse for housing and mental health in Manitoba. This model identifies three levels of policy involvement. The first level is the policy subsystem that includes the universe of

actors and institutions that have any interest in a given policy field. Actors and institutions that engage regularly in discussions about policy issues and options constitute the second level called the discourse community. The smaller group of actors that make policy decisions is called the policy network. Within these levels are three categories of actors and institutions, namely the international system, the state and society.

International System

The influence of internationalism on domestic public policy is being increasingly recognized (Howlett et al., 2009). While this influence is more evident in trade and financial areas, international pressure also permeates public policy. For example, fiscal constraints and government desires for cost containment in an environment of economic globalization created pressures for federal and provincial governments to open up the public health care system to private markets (Morrow, 2004). In addition, international documents can be influential. For example, the need to implement health promotion frameworks including addressing the link between housing and mental health has been articulated internationally (World Health Organization, 2007). International influence can also occur through knowledge and expertise exchange. Initiatives implemented in other countries that have a longer history of addressing issues of housing and mental health can be examined for their relative success and appropriateness for implementation in Manitoba.

The State

Responsibility for public policy decision making in Canada is held by elected officials (the executive and legislators) and appointed officials (members of the

bureaucracy) (Howlett et al., 2009). Canada has a federal parliamentary political system which has distinct levels of government without a clear hierarchical relationship. As documented in the Constitution Act, 1867 and the Constitution Act, 1982 (Government of Canada, n.d.), the federal and provincial governments have distinct legislative powers over areas of government concern. Matters pertaining to social issues were assigned to the provinces (Miljan, 2008). Consistent with constitutional democracies, Canada also has an independent judiciary whose responsibility is to interpret the Constitution. However federal/provincial/territorial relationships are directed, not only by the written Constitution and the manner in which it is interpreted by the judiciary but also by unwritten conventions and practices that have evolved over time (Miljan, 2008). In the case of social policy (including health and housing), the division of powers between the federal and provincial governments is ruled by the Constitution, elaborate financial and administrative agreements, and regular complex negotiations between the federal and provincial governments. Added to this mix are additional responsibilities assigned to municipal governments (e.g., zoning bylaws related to housing). Thus the elected and appointed officials in the federal, provincial and municipal governments all have potential roles in housing and mental health service delivery.

Federal Government

Although health and social programs are under the jurisdiction of provincial governments and territories, the federal government can exert influence over programs. For example, one of the federal government's roles related to health is setting and administering the provisions of the Canada Health Act which established five principles for the health system: public administration, comprehensiveness, universality,

accessibility and portability (Health Canada, 2005). The federal government also

provides financial support to the provinces and territories for health and social programs

in the form of cash and tax transfers. Less prosperous provinces like Manitoba also

receive equalization payments (Health Canada, 2005). The federal government can use its

spending power to exert influence over health and social policies by applying monetary

penalties on provinces who, for example, deliver services that violate the principles of the

Canada Health Act. Although the federal government has always had this option, the

Social Union Framework Agreement (SUFA) (Government of Canada, 1999) has

formally recognized this power. It is becoming increasingly important that "both levels of

government articulate a consonance of direction" (Fierlbeck, 2004, p. 353). The 2001,

Framework for Bilateral Agreements Aimed at Affordable Housing (Intergovernmental

Conference Secretariat, 2001) and the 2003 Health Accord (Health Canada, 2003) are

examples of federal/provincial/territorial initiatives to work toward such consonance of

direction for social programs. Beyond specific funding arrangements, Health Canada and

Indian and Northern Affairs Canada, as well as federal Crown Corporations, such as the

Canadian Mortgage and Housing Corporation, all have roles in influencing mental health

housing policy.

In addition to the above roles, the federal government also has a direct role in the

delivery of health and social services to specific groups of people. These groups include

First Nations and Inuit peoples, offenders under the federal corrections service, veterans,

and members of the Armed Forces (Health Canada, 2005). Differences in jurisdiction

over health services, especially related to First Nations and Inuit peoples can create

differences in access to services in Manitoba, particularly in rural and northern communities.

The federal government also has a role in funding non-profit corporations to provide leadership for pressing mental heath related issues. The Mental Health Commission of Canada, funded by the federal government, was established in 2007 to provide "an ongoing national focus for mental health issues" (Mental Health Commission of Canada, n.d.). The Commission has a mandate that includes setting direction for making improvements in mental health policies and services, reducing discrimination related to mental health issues, and disseminating information about mental health and mental illness. This mandate suggests a role of the Commission for increasing public discourse about, and providing evidence for, policy alternatives. For example, the Commission's *Research Demonstration Projects in Mental Health and Homelessness* aim to establish evidence for policy options that best meet the needs of people who experience mental illness and homelessness (Mental Health Commission of Canada, n.d).

Provincial Government

Manitoba, like other provinces, has responsibility for social programs, including health and housing, as documented in the Canadian Constitution. Manitoba funds health insurance and social programs with assistance, in the form of transfer payments, from the federal government. Within the Government of Manitoba, the Treasury Board, Minister of Health, Manitoba Health, and the Mental Health and Addictions Branch, the Minister of Family Services and Housing, the Department of Family Services and Consumer Affairs, and the Housing Division all have central roles in policy decisions about mental

health and housing policy. In addition, Employment and Income Assistance also has a stake in the discussions due to the relationship between social assistance and core housing need. Some units like the Mental Health and Additions Branch have a specific mandate related to people living with mental illness. Other departments have smaller roles within the larger provision of services. For example, the Department of Family Services funds licensed residential care facilities for people with mental illness in addition to many other social housing programs.

As is illustrated by this list of provincial state actors, the issue of mental health and housing includes multiple sectors creating the potential for diffusion of responsibility and accountability, as well as complexity in policy decision making. Added to this complexity is the establishment of entities run by Boards of Directors with sweeping mandates to deliver services. This is illustrated in the health portfolio; the provincial government oversees the system of mental health services offered within the province and provides overall policy direction to the organization of health services that is largely managed by the 12 Regional Health Authorities (RHAs) (Manitoba Health (n.d.). The RHAs have responsibility for the planning, delivery and management of health services, including most mental health services, in the province (Manitoba Health, n.d.). In an effort to coordinate policy development for people with mental health problems and social housing needs, the Cross Department Coordination Initiatives unit was established in 2007. Its purpose has been to coordinate the efforts of Manitoba Health and Healthy Living and Family Services and Consumer Affairs, in collaboration with RHAs, to improve policy and service coordination (Manitoba Family Service and Consumer Affairs, n.d.).

Municipal Governments

Municipal governments have responsibility to create and enforce zoning bylaws within their jurisdiction. They also have responsibility for policing and city planning which can have an impact on secure and pleasant housing environments with access to transportation and services. Municipal governments also can contribute capital costs to low income housing.

Society

Although elected and appointed state officials have ultimate responsibility for public policy decisions, many other groups and actors can have considerable influence in policy development. The structures and actors particularly relevant to mental health and housing are business, labour, non-profit service delivery, housing and neighbourhood organizations, non-profit advocacy and self-help organizations, professional organizations, think tanks, and the media.

Business

Private market landlords of rental properties have business interests within this policy subsystem. Social housing may be part of the private market delivery in which private market landlords own property that is rented or leased by individuals or groups who obtain public housing subsidies. Housing planners, developers and architects may all have an interest in social housing options.

Labour

Organized labour (i.e., trade unions) may have an interest in social housing initiatives because of the potential for human resource demands related to building new housing. In addition, renovation of existing units may also create additional opportunities for labour demand. However, the extent to which these unions would engage in policy debates about such a small and specific an area as mental health housing may depend on the relative level of impact. For example, new housing in remote areas with depressed economies may engender more interest than in areas with larger demand for labour.

Non-profit Service Delivery, Housing and Neighbourhood Organizations

A wide variety of non-profit organizations that provide services to people with mental illness and those who provide services to people who are, or who are at risk for, homelessness are likely to be key actors in this policy subsystem. These organizations can include hospitals providing mental health services, community organizations providing housing supports to people with mental illness, community health centres that have relationships with specific neighborhoods, organizations that provide shelter to people who are homeless, and other organizations that operate supported housing for people with mental illness. In addition, organizations that provide services to specific populations such as aboriginals may also have an interest in mental health housing.

Non-profit Advocacy and Self-help Organizations

Advocacy and self-help organizations with an interest in mental health and housing may be part of the policy sub-system. Other groups also have an interest in this policy area including groups with a general interest in social housing or groups interested

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in housing with a focus on the interests of people with disabilities, people from special age groups, including seniors, children and youth, people from various cultural backgrounds including aboriginal people and immigrants, and people living in poverty.

Professional Organizations

Specific professional organizations may also engage in policy debates. Medicine has enjoyed a privileged position in health care policy making. Since the 1970s and 1980s provincial governments appear to be less willing to be influenced in policy formulation by professionals and more willing to include consumers, family members and non-government organizations in the policy discourse (Kirby & Keon, 2004). The traditional role of psychiatry to admit, discharge, and assume ultimate responsibility for the care of patients within institutions places it in a dominant position over other professionals and within the bureaucracy of the institutions. Physicians have assumed a powerful role under the provisions of the provincial Mental Health Act in relation to the care of people who fall under the provisions of the Act (Province of Manitoba, 1998).

In relation to community care, physicians assume a powerful position as gatekeepers to other health services and medicine is the only mental health related profession whose services are covered in the community under the Canada Health Act (Kirby & Keon, 2004). Calls for alternate service delivery models to address the needs of people with mental illness (Craven & Bland, 2001), and who are homeless (Shortt, Hwang, & Stuart, 2006) in primary care settings may be of particular interest to medicine because of their pressure to change traditional practice. Other health care professionals

also may have an interest in this policy area due to the possibility of shifts in previously entrenched service delivery models.

Think Tanks and Research Organizations

Think tanks and research organizations can also influence public policy by directing research funds and targeting messages to decision making. Some interest in the policy area of mental health and housing has been expressed by some research organizations and think tanks. For example, the Canadian Institutes of Health Research has expressed interest in the issues of health and homelessness by sponsoring a symposium on the topic in 2002 (Human Resources and Social Development Canada, 2006). Likewise, the Institute for Research on Public Policy published an article on housing as a social determinant of health (Bryant, 2003). More directly related to mental health and housing, CIHI (2007) recently released a report that addressed issues of mental health, homelessness and risk of homelessness.

The Media

Media can reflect and create public opinion. Politicians, with their interest in re-election, are acutely aware of public opinion. Therefore the media can play a role in perpetuating stereotypes or shifting opinion that can influence policy change. The stigma, prejudice and discrimination faced by people with mental illness have been well documented (Kirby & Keon, 2004) and media appears to play a role in the misrepresentation of people with mental illness (e.g., Day & Page, 1986; Matas, el-Guebaly, Peterkin, Green, & Harper, 1985). Recently, media reporting of mental illness appears to have improved (e.g., Corrigan et al., 2005; Kisely & Denney, 2007) and

targeted efforts to educate journalists have been implemented to promote more sensitive reporting (Skehan, Greenhalgh, Hazell, & Pirkis, 2006). Sensitive and accurate reporting of mental health and housing issues can bring the public's attention to the policy area creating opportunities for change.

Conclusions

This overview of the importance of housing for people living with mental illness and the policy actors with an interest in this policy field highlights the complexity of the policy subsystem. Mental health and housing policy bridges federal, provincial/territorial and municipal governments and crosses sectors and government departments. Diverse societal structures and actors have an interest in the policy field. With recent renewed attention, this policy subsystem may be evolving with new interactions between policy actors. One of the opportunities within a mental health and social housing policy subsystem may be the inclusion of citizen-users of mental health services in policy decision making.

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Chapter 3: Citizen and Citizen-user Participation in Policymaking

How Citizens Participate in Policymaking

Canadian citizens have had multiple roles in contributing to health policy decisions. These roles have been tied, to varying degrees, to formal levels of public policy decision making. Citizens have become elected to public office through federal, provincial and municipal elections. Citizens have roles in the governance of health institutions through membership on boards of health and social service agencies. They also have acted as protectors of the public through lay membership on professional regulatory bodies (Abelson & Eyles, 2004). The public has participated in submissions to government commissions such as the Commission on the Future of Health Care in Canada (Romanow, 2002), priority setting for health services (Abelson, Eyles, McLeod, Collins, McMullan, & Forest, 2003), and the development of clinical policy recommendations (Dobrow, Goel, Lemieux-Charles, & Black, 2006).

Citizens also influence health policy through the courts. Court challenges to the Charter of Rights and Freedoms related to health care have been few and mostly unsuccessful, but those that have succeeded have resulted in changes to government policy (Greschner, 2004). Even the presence of challenges before the courts may influence policy by enhancing the discourse and public opinion about an issue and encourage government action.

Citizens also participate through their membership in consumer, self-help and advocacy organizations. These organizations often act as pressure groups that interact with key government decision makers to influence the policy discourse.

Despite these opportunities open to Canadians, the degree to which citizens effectively participate in health policy debates remains minimal. To a large extent, health policy remains what Coleman and Skogstad (1990) describe as a closed corporatist system that is not receptive to new actors or new ideas creating multiple challenges to increasing citizen participation in health policy discourse.

The involvement of citizen-users in mental health and housing policy decisions can occur at multiple levels in the variety of ways described above. Although citizen-users can become state actors through the Canadian electoral system, there are many structural barriers that make it difficult for citizen-users (and many others) to become elected officials. Likewise, appointments to positions within the civil service or as members of boards of directors of Crown Corporations or Regional Health Authorities and other governmental or quasi-governmental institutions are unlikely to include opportunities for many citizen-users. For example, surveys examining the demographic composition of governance positions in Canadian health authorities have consistently suggested that citizens in these positions tend to be middle aged and well educated (Chessie, 2009; Lewis et al., 2001; Lomas, Veenstra, & Woods, 1997) rather than demographically representative of the broader community.

Thus the opportunities for involvement in policy decision making are typically only open to a select few; however, citizens have access to policymaking as social actors. Although these roles may not constitute actual decision making they can influence the policy decisions that are made.

Howlett and colleagues (2009) matched the five stages of the policy cycle as described in Chapter 1 to actors that tend to be involved in the policymaking process to illustrate the stages in which more or fewer actors may be involved. In the agenda setting stage the largest number of policy actors tend to be involved; in the policy formulation stage a smaller subsystem of policy actors engage in dialogue about policy solutions; in the decision-making stage only those with authoritative power make decisions; in the policy implementation stage the smaller subsystem is again involved; in the policy evaluation stage all those with an interest in the issue may be involved (Howlett et al., 2009). Currently, the greatest opportunities for citizen-users to become involved are in the agenda setting stage in which problems are identified and action is demanded of the government, and in the evaluation stage in which people can voice their opinions about the value of policy decisions and implementation. These opportunities for involvement are often informal. However, the commitment for greater citizen involvement in health and social policymaking (Government of Canada, 1999) suggests that governments are interested in shifting to a more open subsystem that offers greater opportunities for citizen-user involvement in the stages of policymaking that are more proximal to decision making. Within Canada's representative democracy, public policy decisions are the responsibility of governments. Therefore, government commitments for greater involvement can create a more open policy subsystem so citizen-users have more influence over those decisions.

How Citizen-User Involvement Is Situated within Health Policymaking

The need for a mental health services system that promotes the recovery of people living with mental problems has been identified as an important policy goal for

transforming mental health services and supports in Canada (Standing Senate Committee on Social Affairs, Science and Technology, 2006). A recovery oriented system protects the rights of people living with mental illness to have equal opportunities in society and to experience empowerment and self-determination (Anthony, 1993). It facilitates the engagement of people with mental health problems in decisions about their own care and as citizens in social and political life. In addition, participation in program and policy decisions has been identified as a helpful factor for supporting recovery (Onken, Dumont, Ridgway, Dornan, & Ralph, 2006). Thus, involvement in policymaking can be an indicator of successful engagement of people as citizens in a recovery oriented service system as well as a facilitator of personal recovery. Mezzina and colleagues (2006) argued that citizenship may be both a precondition and consequence of recovery.

Despite some formal opportunities for involvement in health policymaking, there is general consensus in the literature that citizen-users face multiple barriers to accessing policymaking processes (e.g., Barnes, 2002). These barriers stem, in part, from the historical context of health policymaking which has been a closed system dominated by professionals and bureaucrats. In the case of mental health policy, Mulvale and colleagues (2007) showed how the historical organization of mental health services in Ontario emphasized institutionalization and physician policymaking dominance and how the public lacked interest in the policy area.

To attempt to shift decision making processes and promote accountability, Canadian federal and provincial governments have documented national and provincial commitments to citizen involvement in policymaking (e.g., Government of Canada 1999). In some cases, governments have mandated involvement of citizen-users. For

example, the provincial government of Manitoba documented its expectation that Regional Health Authorities include service users in service development (Manitoba Health, 2003). While these commitments promote citizen-user involvement, they are relatively silent on the ways for these expectations to be actualized.

One of the ways that governments have attempted to involve citizen-users is through top-down formal mechanisms such as advisory committees and community forums. These mechanisms have received considerable attention in the literature in terms of their purposes and level of decision making (e.g., Rowe & Frewer, 2005). Unfortunately, little attention has been paid to the outcomes (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006). In addition, the ways that these forums are constructed has limited the involvement of citizen-users. For example, standards of behaviour common in the exchanges within committees and forums have not necessarily been those deemed important by all consumer participants (Church, 1996). In addition, many citizen-users face barriers to participation because they require resources and supports such as transportation, encouragement, peer support, and access to plain language information (Restall & Strutt, 2008) that many citizen-users may not have. As well, decision makers may be skeptical about whether citizens can participate in complex policy discussions about highly technical issues (Health Council of Canada, 2006). This may be a particularly salient issue for citizen-users who regularly face the consequences of stigma within society (Kirby & Keon, 2004). In addition, individuals and groups who hold traditional power in policy decision making may not see the benefits of deliberative forums because they do not want to share power (Hendriks, 2006) and may actively, or covertly, resist their implementation.

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Process, Outcome and Context Criteria for Involvement Mechanisms

The following section outlines the literature on the processes, outcomes and contextual factors influencing citizen involvement in policy making. The approach taken in this section is to identify the most promising processes, the desired outcomes and what is known about the contextual factors that influence involvement. The information is presented as a framework that identifies key criteria in each of these three areas, evaluation questions that could be used to determine whether the criteria were being met, and proposed indicators of successful involvement mechanisms. Appendix A summarizes process criteria, the relevant evaluation questions that relate to the criteria and indicators of good practices related to processes. Appendix B summarizes the literature on the expected outcomes of participation with relevant evaluation criteria and indicators of positive outcomes. Appendix C summarizes literature on contextual factors that are believed to influence participation. Due to the relative lack of literature related to context, indicators have not been identified. Literature has been drawn from works related citizen participation in health and other public policy areas, particularly environmental decision making.

Process Criteria

The development of specific process criteria against which to evaluate involvement has been the most common approach to evaluation (Rowe & Frewer, 2000). In a review of the literature, Rowe and Frewer (2004) identified multiple process criteria that were used in effectiveness evaluations of public participation exercises from 1981 to 2004. These were summarized by Abelson and Gauvin (2006) as 24 separate criteria.

Despite the importance attributed to process criteria in evaluations of involvement mechanism, there has been little consistency in definitions of criteria or approaches to evaluating process (Rowe & Frewer, 2004). A few of the more influential approaches to using process criteria will be discussed below.

Arnstein (1969) published a classic article on citizen participation that described "eight rungs on a ladder" (p. 217) to describe various levels of participation or non-participation in environmental decision making. This ladder was an initial step in establishing process criteria. Arnstein named these levels: manipulation, therapy, informing, consultation, placation, partnership, delegated power and citizen control. Since its original publication Arnstein's ladder has been modified and refined to develop more elaborate frameworks of evaluation of public participation. In addition, Tritter and McCallum (2006) argued that Arstein's ladder, with its emphasis on power in decision making has not adequately accounted for the complexity of the process or the diversity of participants.

Rowe and Frewer (2005) proposed a typology of participation mechanisms that included three levels of involvement: communication, consultation and participation. Communication involved dissemination of information in a unidirectional fashion from a government or organization to citizens. Consultation involved public institutions seeking input on a policy. Consultation mostly involved flow of information from citizens to the institution, although some background information could be provided by the institution to citizens. The third level, participation, involved a bi-direction flow of information between public institutions and citizens. This exchange of information can influence understanding of issues and influence decision making.

Another influential work is that of Webler (1995) who designed a model to evaluate participation in environmental decision making. Webler proposed that public participation is a normative procedure and the goals of that procedure should be fairness and competence. Fairness referred to the opportunities for anyone to participate, assert their opinions, protect their interests, and influence the final outcomes. Competency referred to procedures that provided participants with knowledge and tools to make good decisions. The framework (Webler, 1995, p. 63) set the need for fairness and competency in a matrix along with organizational activities. With regard to fairness, participants' needs to attend, initiate, debate and decide were viewed in the context of agenda and rule making, moderation and rule enforcement, and discussion. With regard to competence, participants' needs for "access to knowledge and interpretations" and "best procedures for resolving disputes about knowledge and interpretations" (Webler, 1995, p. 81) were viewed in the context of four types of discourse: explicative, theoretical, practical and therapeutic. Within this matrix, Webler developed multiple criteria against which an overall assessment of fairness and competency of participatory forums could be made.

Process criteria also were used by Rowe and Frewer (2000) in the development of a framework to evaluate participation. They acknowledged that their framework had many similarities to Webler's (1995) although they claimed that their framework had broader applicability. Rowe and Frewer's (2000) nine criteria were: a) representativeness of the participants, b) independence of the process, c) early involvement of participants in the process, d) the influence of the process on policy, e) transparency of the process f) resource accessibility (sufficient resources for participants to achieve their mandate), g) a

task definition that clearly describes the type and scope of the participation, h) structured decision making and i) cost-effectiveness.

The types of mechanism that can be used for citizen involvement are diverse. Health Canada (2000) listed 45 different mechanisms that could be used to engage citizens in participatory processes. Participatory mechanisms can vary greatly among each other and in the ways that they are applied (Rowe & Frewer, 2005). Some mechanisms such as focus groups are more suited to consultation; other mechanisms such as advisory groups are more suited to participation. These mechanisms have been reviewed in relationship to their purposes, strengths, and limitations elsewhere (see, for example, Abelson & Gauvin, 2004; Health Canada, 2000; International Association for Public Participation, 2006).

Although multiple process criteria have been identified in the literature, six criteria are salient to many of the diverse ideas and concepts discussed in the literature. These criteria are: goals of citizen involvement, level of participation (including the extent of participants' role in decision making), representation, opportunity for discourse, access to information, and resources required. The *goals* criterion refers to the extent to which the purposes of citizen involvement have been articulated and agreed to by all involved. This criterion is related to Rowe and Frewer's (2000) criterion of task definition and is particularly important to the ability to measure outcomes. The *levels of participation* criterion consists of three levels of participation described by Rowe and Frewer (2005): communication, consultation and participation. These levels are consistent with levels proposed internationally (OECD, 2001) and with levels discussed by Gauvin and Abelson (2006) for application to Canadian health policy. Involvement

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mechanisms have been categorized according to the levels of participation they enable (Health Canada, 2000; Rowe & Frewer, 2005). These levels infer, as Arnstein (1969) suggested, the amount of control that participants have over decisions. Within the context of health policy decision making in a representative democracy, the levels are limited to those that assume that public officials retain ultimate control over public policy decisions. The levels of participation reflect the degree to which citizen-users influence the final decisions. *Representation* refers to the methods with which people are recruited to participate and likelihood that those methods will result in participants who represent those who are affected by the issue and the range of interests, opinions and perspectives about the issue. This criterion considers the whether anyone who wants to participate has the opportunity to participate (Webler, 1995) and is widely used in evaluations of participatory processes (Rowe & Frewer, 2004). *Opportunity for discourse* relates to participants' opportunities to initiate ideas, debate ideas and make decisions (Webler, 1995) during the participatory process. *Access to information* refers to the opportunity for participants to obtain information to increase their knowledge about the issue under discussion. This criterion is consistent with one of Webler's competency criteria. Also, other research suggests that sharing information in participatory processes is important to citizens (Abelson et al., 2004; McIver, 1998). The use of evidence in public policy decision making is also deemed important and the extent to which participants have access to research evidence and other sources of information related to the policy issue can contribute to their ability to generate and consider policy options. Finally, *resources and supports* relates to the time and monetary resources necessary to implement the mechanism. Time and cost-effectiveness have been identified as evaluation criteria in the

literature (Rowe & Frewer, 2000; Sewell & Phillips, 1979). This criterion also includes other forms of support that can facilitate citizen-user participation such as social support and advocacy (Restall & Strutt, 2008).

Outcome Criteria

Outcome criteria have been less systematically addressed in evaluations of citizen involvement and few measures exist to evaluate the effectiveness of involvement mechanisms in influencing policy decisions. Like process criteria, there is little consensus on the criteria to evaluate. Abelson and Gauvin (2006) summarized 19 outcome criteria from Rowe and Frewer's (2004) review of evaluation studies. Many of these criteria addressed how the participation processes influenced decision making, policy and institutional practices. Criteria can also be drawn from literature related to the rationale for citizen participation (e.g., Beierle & Cayford, 2002; Fiorino, 1990; OECD, 2009). Although this literature can be theoretical rather than evaluative, it provides insight into the expectations that people have related to the outcomes of citizen involvement.

The rationale for increasing the roles of citizens in policymaking includes substantive benefits (making better policy), normative benefits (strengthening democracy) and instrumental benefits (improving government accountability and public acceptance) (Beierle & Cayford, 2002; Fiorino, 1990; OECD, 2009). Although not as high a priority for governments (OECD, 2009), citizens often cite the importance of the personal benefits of involvement, such as learning more about an issue (e.g., Rowe, Marsh & Frewer, 2004). Appendix B summarizes the potential social and individual outcomes that may arise from citizen-user involvement.

Instrumental Benefits

Instrumental arguments claim that involvement of citizens will facilitate government accountability and public acceptance in policy formulation (Barnes, Newman, Knops, & Sullivan, 2003; Beierle & Cayford, 2002; Charles & DeMaio, 1993; Coney et al., 2004; Fiorino; 1990; Gauvin & Abelson, 2006). Through participation, conflicts among policy actors and groups may decrease (Beierle & Cayford, 2002). In health related policy issues, public confidence in decisions may increase (Health Canada, 2000) as citizens gain a greater understanding of decisions (Coney et al., 2004). The process of citizen engagement may promote trust in institutions (Abelson & Gauvin, 2004) including governments (OECD, 2009) and in relationships among users and service providers, and within communities (Farrell, 2004). Citizen involvement may be a way of increasing understanding of policy issues and for governments to communicate directly with their citizens (Phillips, 2001). Citizen engagement may be used by governments to hold each other accountable for commitments and agreements. For example, Philips (2001) suggested that Social Union Framework Agreement (Government of Canada, 1999) identified the roles of citizens as both "watchdogs" (p. 9) and as participants in policy formulation. Thus, citizens become the means by which the provincial and federal governments hold each other accountable for agreements. The same argument could be made for the relationship between provincial governments and Regional Health Authorities. Citizen engagement in Boards of Directors and Health Advisory Councils could be one means of facilitating broader accountability mechanisms.

Participation is also believed to be important for building social capital and community capacity (Barnes et al., 2003). Participation may enhance the capacity of communities to respond to health issues through the development of new organizational structures, leaders and other resources that may have long term impacts (Health Canada, 2000; Phillips & Orcini, 2002; Thurston et al., 2005).

Substantive Benefits

Substantive arguments for participation claim that citizen participation results in better policies and services (Barnes et al., 2003; Beierle & Cayford, 2002; Coney et al., 2004; Fiorino; 1990). Citizens have perspectives that professionals do not have. These perspectives can contribute to decisions that can create better health programs and services (Coney et al., 2004; Health Canada, 2000) and that better meet the needs of communities (Church et al., 2006). Some (e.g., Coney et al., 2004) have argued that resources will be better utilized and the efficiency of health services improved.

One of the important outcomes of participation in health policy development is the extent to which citizen participation improves the health status of populations (Charles & DeMaio, 1993; Thurston et al., 2005). The overall goal of the Canadian health system is that "every person is as healthy as they can be - physically, mentally, emotionally, and spiritually" (Canadian Federal, Provincial and Territorial Governments, n.d.). Therefore, citizen participation should advance that goal. The challenge may be in finding both short term and long term indicators of the relationship between participation and movement toward the goal. Thurston and colleagues (2005) proposed that increasing the size and influence of individuals and groups involved in policy debates may be an

indicator of population health because the skills learned can be transferred to larger community issues as an element of community capacity building.

Normative Benefits

Normative arguments for participation claim that citizen participation in public policymaking will promote a stronger democracy (Barnes et al., 2003; Beierle & Cayford, 2002; Fiorino; 1990; Gauvin & Abelson, 2006; OECD, 2009) and is a right of people who are affected by the decisions (Young, 2000). The normative role of deliberation inherent in many participatory forums is that it can influence the views of others. If the objective of deliberation is to promote "a mutual understanding and, ideally, agreement on the normative legitimacy (justice of fairness) of a policy among all those whose needs and interests are affected by it" (Dickinson, 2004, p. 254), then social learning is expected to occur among all participants in the discourse (Dickinson, 2004).

Barnes (2002) suggested that participatory processes should address enhanced citizenship, social exclusion, ways that policy is created and implemented, and the quality of services. These social change goals suggest that citizen involvement should fundamentally change the ways that power is exerted in policy development. Indeed, one of the purposes of citizen involvement may be to shift power away from professionals and toward greater inclusion of others, such as consumers and family members, in policy discourse (e.g., Kirby & Keon, 2004). If one of the main purposes of citizen participation is to rebalance power (Contandriopoulos, 2004) then shifts in power balances toward the least powerful (Lister, 2002) should be a goal of citizen involvement.

Personal Benefits

Citizen and citizen-user involvement may have personal benefits to those who participate. It is believed that participation in health system policy development has a direct benefit to citizen-users through increases in self-esteem (Crawford et al., 2002), people discovering their own strengths (Barnes & Shardlow, 1997), and greater empowerment (Consumer Focus Collaboration, 2001; Mental Health Branch, 1999). Participants may perceive that they benefited from the experience through increased knowledge and social connections (Delli Carpini, Cook, & Jacobs, 2004; McIver, 1998). Individuals may also benefit directly from better policy decisions.

Abelson and Gauvin (2006) suggested that an intermediary outcome of citizen involvement may be the impact that the involvement process has on key officials and decision makers. Organizational learning through officials involved in involvement processes may change the way organizations do business and the skill with which officials can engage the public (McIver, 1998). Officials may become more accountable for the decisions they make. As well, a greater understanding of the perspectives of citizen-users may change decision-makers' approaches to other policy issues that are not directly connected with the immediate involvement process.

Negative and Unintended Outcomes

Although the goals of citizen-user involvement are focused on positive outcomes, these processes may also have negative or unattended outcomes. These negative outcomes can affect citizen-users, officials and society at large. For example, poor quality involvement mechanisms may be counterproductive (Delli Carpini et al., 2004). Poorly

designed consultative and deliberative forums and those in which the outcomes appear to be predetermined or are not tied to decision making may be destructive to trust and relationships between citizens and decision makers. Such processes may create cynicism among those who participate if their expectations are not met (Abelson et al., 2004) and people may become reluctant to further engage.

Involvement mechanisms may not be efficient in relationship to the balance of costs and benefits (Abelson & Eyles, 2004). Costs accrue to governments and public institutions as well as to individuals and other organizations. Involvement may increase stress on citizen-users (Barnes & Wistow, 1994). The involvement of non-profit organizations may create opportunity costs as they expend time and resources in involvement mechanisms at the expense of other activities such as working directly with clients (Thurston et al., 2005).

Context Criteria

The third area of importance in evaluating participation is the context in which participation occurs. Theory papers on participation have acknowledged the importance of contextual variables and their influence on the process and outcomes (e.g., Chess, 2000; Renn, Webler & Wiedemann, 1995). Despite acknowledgement of the influence of these factors, Rowe and Frewer (2004) observed that most evaluation studies seldom do more than mention context variables in broad terms. However, there have been three recent research contributions from the UK (Newman, Barnes, Sullivan & Knops, 2004) and Canada (Abelson, Forest, Eyles, Casebeer, Martin & Mackean, 2007; Thurston et al., 2005) with direct applicability to health policy.

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Newman and colleagues (2004) reported on a synthesis of 17 case studies from forums in the United Kingdom that engaged citizens in deliberation about policies and services that included health. They noted several contextual variables including, a) the broad political landscape, b) institutional mechanisms and c) the capacity of the organization to engage in participatory forums. They also noted that the experiences and interpretations of participants, including previous experience with social action, appeared to influence the perspectives that participants contributed to the deliberative forms. Another factor was the meanings that participants placed on participation and how their symbolic constructions of the forum could enhance or detract from the capacity of the forum to reach its potential. Finally, Newman et al., (2004) found that the symbolic constructions of participants by officials were important. These symbolic constructions included distinguishing between whether officials saw citizen participants as users, the public, consumers or as "experts" who could make valuable contributions to the deliberation.

In a Canadian study, Thurston et al. (2005) reported on five case studies in the Calgary Health Region. This study used qualitative methods in the form of interviews, document reviews, observation and focus groups (p. 239). Using a grounded theory approach, Thurston et al. developed a conceptual framework that situated public participation within the context of health policy. They identified five major contextual elements. The first element was the participation process. This element included the mechanisms used, who is involved and why, credibility, history and mandates of the participation initiative, and the formal and informal rules surrounding the initiative. The second element was related to policymaking in the region. This element related to how

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"space" was made for the initiative to influence policy. Space for influence could be impacted by such things as organizational culture, how problems were identified and resolved, whether the initiative was targeting governance or operational issues, and whether decisions would affect formal or informal policies. The third element was the social context which included both political and symbolic institutions. This element concerned political factors such as funding arrangements. Symbolic institutions such as race, gender and religion were also conceived as having an influence on how the political space for policy influence was created and maintained. Thurston and colleagues identified the policy community as the fourth element of their model. This element considered the policy actors and the impact of the participatory initiative on building capacity in the policy community. Finally, Thurston and colleagues noted that the health of the population as an important context. They saw improvements in population health as an important goal of participatory initiatives.

Abelson et al. (2007) used a conceptual map to inform the investigation of the role of various contextual variables on a deliberative mechanism delivered in five Canadian provinces. The map included five elements: a) political contexts related to relationships and trust, b) community related to the characteristics of the population, c) research-decision maker relationships, d) organization context related to the commitment of organization staff to the initiative, and e) decision making considering the kind of issues being considered and the time frame for decisions (p. 2119). Abelson and colleagues applied a quasi-experimental comparative design and identified several findings related to context including that the application of methods had to match the context and that organizational leadership and commitment were important.

These studies described a broad range of contextual factors that can influence citizen involvement from personal and interpersonal factors, to those related to institutional and socio-political environments. Historical perspectives are also important. Mulvale, Abelson, and Goering (2007) demonstrated how historical mental health policy decisions created a policymaking context in Ontario in which mental health policies were given lower priority than other health policy areas, hospital and physician services were emphasized, physicians were given a privileged and dominant place in mental health policymaking and mental health policy had limited public profile. Within this context citizen-user involvement may face even greater challenges than other areas of health policy.

Summary

Although there is general consensus about the importance of processes, outcomes and contexts for the application of involvement mechanisms to facilitate the participation of citizen-users in policy development, the application of these factors to health policy is poorly understood. A more substantial body of literature exists in other areas, particularly environmental policy. Several process criteria have been identified in the literature for implementing fair and competent processes. The potential normative, substantive, and instrumental outcomes of involvement and the potential impacts on participants have been identified. In addition, many authors have acknowledged the importance of context and a few have identified some specific contextual variables that may influence the implementation of involvement. However, there is no consistent typology of contextual elements (Abelson et al., 2007; Rowe & Frewer, 2004) or clear understanding of the most important contextual variables. There are few standardized measures of involvement

processes, outcomes and context. Little is known about the link between involvement

processes, how they are connected to outcomes and how context impacts both process

and outcomes.

Grassroots Approaches to Citizen-user Engagement

The preceding discussion has focused on governments' use of involvement

mechanisms to engage citizens and citizen-users in policy discourse. However, citizen-

users also engage in policy discourse through other means that constitute more grass

roots approaches. The tradition of civil rights movements and social action has not been

as strong in Canada as it has been in other jurisdictions such as the United States.

However, the forces of these movements have transcended borders through, for example,

the independent living movement.

The independent living movement gained momentum in the United States in the

1970s with the development of centres for independent living (DeJong, 1979). It provided

a distinct alternative to the rehabilitation and medical model paradigms to addressing the

needs of severely disabled people that were prominent at that time. The movement

stressed that many of the "problems" experienced by people with disabilities resided

within environments rather than within the individuals with disabilities; solutions

emphasized advocacy, self-help, and consumer control (DeJong, 1979).

The philosophies of independent living resonated with the ex-patient movement,

developed among people who had been patients of the mental health system, during a

parallel time frame (Chamberlin, 1990). The ex-patient movement emphasized self-help

and advocacy, and demanded the inclusion of ex-patients in discourse forums to which

they had previously been denied access. It also emphasized developing alliances with other disability groups that adhered to the principles of independent living and self-help as potentially powerful mechanisms for creating positive legislative changes (Chamberlin, 1990).

In Canada, Independent Living Centres have also taken a cross-disability focus for self-help, peer support and advocacy for the rights of people with disabilities. Although Hutchison and Pedlar (1999) found that only a small minority of users of Independent Living Centres were mental health consumers, they argued that the independent living philosophy was consistent with the mental health reform ideals that were articulated in the 1990s. Independent living philosophy included advocacy for both individual and community change (Jongbloed & Crichton, 1990) but the impact of Independent Living Centres had been perceived to be more related to individual advocacy (Hutchinson, Pedlar, Dunn, Lord, & Arai, 2000).

In addition to Independent Living Centres, mental health disability specific organizations have also been an important means for citizen-users to participate in policy discourse. Hutchinson and colleagues (2007) distinguished between user-led disability organizations such as the National Network on Mental Health and non-user led organizations such as the Canadian Mental Health Association. However, their findings also suggested some ambiguity about the definition of user-led because disability organizations that were traditionally led by professionals or family members have evolved so that more users are on boards of these organizations. McColl and Boyce (2003) suggested a framework for disability advocacy organizations that reflected a continuum of ideological and practical factors reflecting diversity in organizations that

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may be more helpful in understanding perspectives than a strict dichotomy. They also

noted ideological shifts in disability organizations "from service to advocacy, from

confrontation to collaboration and from clients to consumers" (p. 389). The tendency

toward greater collaboration is evidenced in the partnerships among diverse disability

organizations and professional groups in coalitions such as the Canadian Alliance on

Mental Illness and Mental Health (n.d.) to advocate for systems change.

Disability organizations that have systems advocacy as a primary mandate of their

organization can provide citizen-users with opportunities to engage actively in policy

debates, but what is known about the impact of these organizations on public policy?

Some important impacts have been attributed to consumer organizations such as the

inclusion of equal rights for people with disabilities entrenched in the Canadian

Constitution (Dunn, 2002). However, the force of these organizations may have eroded

over time (McColl & Boyce, 2003) and overall impacts on inclusion and citizenship

remain unsatisfactory to many advocates (Prince, 2004).

Conclusion

This review of the ways that citizen-users participate in policymaking has

identified both top-down approaches that are currently popular with governments in

engaging citizens and citizen-users in more or less formalized policy discourses. The

review has also identified the bottom-up grass roots approaches that have been a legacy

in policymaking for the past several decades. The focus of the studies providing the

foundation for the thesis research, as discussed in the next chapter, was on the important

structures and processes for citizen-user involvement. The thesis research focused on the

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desired outcomes of involvement as well as the contextual factors that influence the

mechanisms by which citizen-users engage with policy decision makers with the intent of

influencing policy.

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Chapter 4: Summary of Previous Research

This research has been built on the researcher's previous research that provided the initial stages of development of a framework for understanding citizen-user involvement in health and social policy. The following sections will describe the two phases of research served to underpin the thesis research.

Phase 1: Participation in Planning and Evaluating Mental Health Services

The purpose of Phase 1 was to gain the perspectives of people who use mental health services about the ways in which they would like to be involved in planning and evaluating services and to identify institutional practices that encourage and enable participation. This was accomplished by addressing the following three objectives:

1. To obtain feedback from users of mental health services about current practices related to involving users in the planning and evaluation of mental health services.

2. To obtain the expert opinion of people who use mental health services about the ways services can become more receptive to the meaningful participation of people who use services.

3. To develop a conceptual framework to promote participation of people who use mental health services in service development and evaluation

Participants for Phase 1 were recruited from three RHAs in Manitoba: Winnipeg, Norman and South Eastman. These communities represented diverse geography and socio-cultural environments. Purposeful maximum variation sampling (Patton, 2002) was used to recruit participants with a wide range of backgrounds who had used mental health

services for at least six months in the previous five years. Participants were recruited through a flier that was distributed by service providers and consumer groups. In-depth interviews and focus groups were held with a total of 63 participants. Thirty-seven (37) people participated in one of seven focus groups and 26 people participated in individual interviews. A combination of focus groups and interviews was used for two reasons: to respect people's preferences for choosing their preferred method of participation and to obtain two sources of narrative, the single voice of individual interviews and the blended voices of focus groups. These different sources of narrative allowed us to increase the trustworthiness of the results through the triangulation of data sources (Patton, 2002). This research used a qualitative exploratory design. The University of Manitoba Health Research Ethics Board approved the study. All participants provided written informed consent.

Data was collected over a four month period. A semi-structured interview guide was used for both the focus groups and interviews. All interviews and focus groups were conducted by an experienced interviewer and/or the primary investigator. Focus groups and interviews were audio taped.

Audio-tapes were transcribed verbatim. Transcripts were analyzed with the assistance of NVivo Qualitative Software (version 2.0). Analysis was done by developing a coding scheme based on the initial interview guide. Codes and sub-codes were introduced as themes emerged through line-by-line review of the transcripts. Memo writing during the analysis served to elaborate assumptions and identify comparisons and patterns in the data (Miles & Huberman, 1994).

A summary of the analysis from the initial 30 participants from the urban RHA comprised an interim summary that was use to clarify the themes and concepts developed through an initial analysis of the data. The summary was sent to the participants who were invited to send written comments or attend a workshop. Five (5) people sent written comments and 12 people attended the workshop. Feedback was used to clarify assumptions, enrich interpretation and to seek gaps and alternative explanations in the analysis. This feedback was incorporated into the subsequent data collection and analysis.

The outcome of Phase 1 was a conceptual model for health planners to facilitate citizen-user involvement (Restall & Strutt, 2008). The conceptual model (Appendix D) identified the factors that participants believed enable participation activities. The development of respectful, inclusive and flexible processes was a strong theme that created a basis for the conceptual model. Participants also identified the actions that health planners need to take to facilitate participation in service planning and evaluation. Participants had many opinions about the types of participation activities that should be available to people. They suggested committees, interviews, varied employment opportunities, surveys, writing, story telling and public speaking. Regardless of the activity, participants wanted their investment of time and energy to have tangible outcomes. Participants needed assurances that their involvement would be used to make positive changes rather than to legitimize decisions that had already been made by organizations. There were variations about the level of decision making participants wanted. Some participants were comfortable having real influence about changes to the service system while others wanted to participate by having their stories heard and taken

into account when decisions are made. A published manuscript providing more detail about the methods and results of Phase 1 research is included in Appendix D.

Phase 2: Development of a Tool to Assess Organizational Support for Participation

The purpose of Phase 2 was to use the results of the study conducted in Phase 1, in conjunction with other published literature, to develop an audit tool that could be used by health planners to assess organizational support for citizen-user involvement in health service planning. A preliminary framework for the tool was developed based on the conceptual model as well as the themes and subthemes identified through participant narratives in Phase 1.

The University of Manitoba Health Research Ethics Board approved the study. Seven participants, who had participated in Phase 1 and had agreed to be contacted for future research, were recruited to review the preliminary framework. Three participants were from the geographic boundaries of the Winnipeg Regional Health Authority and two each from the Norman and South Eastman Health Authorities. All participants provided written informed consent.

Through semi-structured interviews participants provided feedback about positive and negative aspects of the framework and indicated whether there were any gaps. Preliminary analysis from these interviews was used to refine and modify the tool. The resulting tool (Restall, 2008) (Appendix E) consisted of five dimensions of involvement identified from the Phase 1 research. These dimensions identified actions that organizations could take to facilitate involvement. The dimensions were: a) the organization provides opportunities for diverse participation activities, b) the organization

uses respectful, flexible and inclusive processes, c) the organization supports citizen-users throughout the participation process, d) the organization promotes citizen-user participation in the decision making process, and e) the organization connects citizen-user participation to the decisions it makes. Each dimension had several criteria with indicators of effective involvement processes that were identified from the perspectives of citizen-users as obtained through Phase 1 research augmented by a review of the literature. These criteria focused on the structures and processes that needed to be in place to create a context receptive to citizen-user involvement. The criteria were intended to be applicable to situations in which organizations convene formal involvement mechanisms and can relate to multiple levels and types of organizational decision making. The audit tool can be used by an organization to assist in planning involvement mechanisms. It can also be used to evaluate the extent to which the organization meets the criteria. The tool provides a framework for evaluation and can be used by an evaluator either internal or external to the organization.

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Chapter 5: Methods

Purpose and Objectives

This study built on the previous phases described in Chapter 4 to further develop the framework and to explore the application and utility of the framework for the implementation and evaluation of citizen-user involvement in policy development. The overall design is summarized in Appendix F. The research involved primary data collection as part of the thesis project. The model developed in Phase 1 (Appendix D), the framework for assessing organizational support developed in Phase 2 (Appendix E), and a list of process, outcome and contextual criteria and indicators for citizen-user involvement drawn from the literature (Appendices A, B & C) provided an initial starting point for the development of lines of inquiry for data collection. The intent was to develop a comprehensive model for the implementation and evaluation of citizen-user involvement.

The research that included primary data collection explored the following questions:

1. How are the outcomes of citizen-user involvement conceptualized by citizen-users and officials?

2. What are the pathways through which the experiential knowledge of citizen-users enters policy process and how can these pathways be strengthened?

3. How do the contextual elements of citizen-user involvement impact the implementation and anticipated outcomes of citizen-user involvement?

Design

Qualitative instrumental case study methodology (Stake, 2005) was used to gain insight into the intended outcomes and contexts of citizen-user involvement as they relate to the application of a model of citizen-user involvement. Instrumental case study uses the particular case to understand a more general issue (Stake, 2005). Thus, a case is chosen for instrumental case study because it is believed that the particular case is one that assists in broadening understanding of the issue. Yin (2003) argued that a case study is appropriate when "a how or why question is being asked about a contemporary set of events, over which the investigator has little or no control" (p. 9). He went on to note that it is an appropriate methodology to study a current phenomenon when the boundaries between the phenomenon and context are unclear. These conditions were met for the overriding purpose of the present study. The phenomenon of citizen-user involvement is inextricably linked to the context in which it occurs. The present study aimed to gain greater understanding about how involvement occurs within this context and how context and processes impact outcomes.

Yin (2003) distinguished case study research from other qualitative methods. He distinguished it from phenomenology and grounded theory both of which are conducted with few, if any, preconceived ideas about a theoretical model. In contrast, case study design requires attention to propositions about a phenomenon and its context. The present study was based on a model developed from the literature and the previous phases of the research program to expand our understanding of citizen-user involvement. The results cannot be generalized to other cases but rather to the theory of citizen-user involvement.

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Choice of the Case

Careful consideration was made for the choice of a case. A case may be a person, an event or an entity and the choice and bounding of the case is dependent on the research purpose (Yin, 2003). However, Wells, Hirshberg, Lipton, and Oaks (2002) noted that the bounding of a case often cannot be accomplished until after data collection or analysis and that what constitutes a case is co-constructed between the researcher and the participants of the research. For instrumental case study designs, the phenomenon under consideration is identified first and then a case is chosen based on the contributions of the case to understanding of the phenomenon (Stake, 2005). A case can be chosen because it is typical but often a case that is unusual is more informative. In addition, cases are chosen based on their availability and potential to inform the issue at the time that the study is done (Stake, 2005; Yin, 2003).

For this research, the phenomenon of interest was citizen-user involvement in health policy development. The case was the policy field of mental health and social housing in Manitoba. This case was chosen for three primary reasons: the conceptualization of a case as a policy issue expanded on previous research in the area, the case was unusual in its complexity, and policy activity in the field provided a unique opportunity for study.

The choice of a policy field as a unit of analysis expands on previous research. Much of the previous research in the published literature on citizen and citizen-user involvement in health policy has focused on evaluating involvement forums, i.e., discrete mechanisms for involvement such as advisory committees and Citizens Juries. Previous

research has compared the same forum in different contexts, different forums in the same context or different forums in different contexts. The current project expanded on this research by using a policy field as the unit of analysis and explored the ways that involvement unfolded around the policy issue. This approach had several advantages. First, it reflected more closely the nature of policy decision making that is influenced by multiple factors over time. Second, it considered the use of multiple involvement mechanisms around a single policy issue. Third, examining a policy issue as a unit of analysis provided the opportunity to better disentangle the power relationships that served to include or exclude potential policy actors in health policy debates rather than only examining their involvement within one opportunity to become involved.

The case of the policy issue of citizen-user involvement in mental health social housing policy is unusual in its complexity. Traditionally, the citizen-user involvement related to mental health issues has been focused within the jurisdiction of mental health services. In recent years, mental health services in Manitoba, outside of First Nations communities, have been primarily administered operationally through the Regional Health Authorities. Thus, opportunities for citizen-user influence related to mental health services occurred through a defined organization and government department. The policy issue of mental health and social housing crossed traditional jurisdictional boundaries, in particular the jurisdictional boundaries of the provincial departments of health and income assistance/housing, creating increased complexity to the policy development. This complexity could provide greater understanding of the phenomenon of citizen-user involvement.

Another reason that this case study was chosen was because there had been recent policy attention to this issue, including, but not limited to, the creation of the Cross Department Coordination Initiative for Mental Health and Housing by the Manitoba government. This suggested that the issue was on the government agenda and therefore could provide an opportunity to investigate a contemporary case. Indeed, as the case study progressed policy activity was evident on several fronts related to this policy issue.

Description of the Case

The case was defined as the policy field of social housing for people with mental illness. The case was bounded by place and time. The policy activity by the Manitoba Government was the focus of the case with primary data collection occurring within the City of Winnipeg during the three month period between September and December 2008. Both key informant interviews and documents provided additional data that situated the case study within a historical perspective.

Data Collection

Case study research typically involves multiple methods of data collection including interviews, documentation review, archival review, observation and physical artifacts (Yin, 2003). Data collection in the present study included key informant interviews, documentation review, and researcher reflective field notes. Multiple sources of data provided rich description of the case and promoted trustworthiness in the final interpretations of the results (Patton, 2002).

Key Informant Interviews

In qualitative research key informant interviews are used to obtain the perspectives of people who have an insider's view on the topics of interest for the case study. Through interviews, key informants can provide information about the events surrounding the phenomenon, their interpretations of the phenomenon and information about other potential key informants or sources of information about the case study (Yin, 2003). Current perspectives on interviewing have noted that these types of interviews are texts that are negotiated between the interviewer and the interviewee (Fontana & Frey, 2005). This means that interviewers bring their own biases and perspectives into the interview situation. Understanding the nature of negotiated text is important in later analysis and interpretation of interview data.

Sample

In the present study, key informants were purposively selected from policy actor groups with an interest in mental health and social housing. Following Flick's (2006) approach to theoretical sampling, the groups were defined *a priori* because they were expected to have differing perspectives of the issues under study. Theoretical sampling occurred within the groups. Theoretical sampling meant that preliminary analysis of data and scrutiny of field notes identified areas in which additional sampling was needed to fill in the categories and themes that arose from the data. The initial sampling frame consisted of key informants from each of the following policy actor groups.

- Citizen-users – Individuals who self-identify as needing mental health and social housing services within the past year.

- Advocacy organizations – Representatives of organizations that frequently provide advocacy on behalf of people with mental illness. Examples of these organizations are the Manitoba Schizophrenia Society and the Canadian Mental Health Association.

- Government officials – Government employees and elected representatives of government who perceive themselves as having influence over mental health and housing policy.

- Service providers from non-profit health and housing organizations – People who provide services to people with mental health and social housing needs.

From among these groups, initial participant selection was based on the criteria that informants were involved in policy debates related to mental health and housing in Manitoba. The sample size was initially targeted at between 12 to 18 participants. Additional participants were recruited to assist in informing the categories and themes that emerged during initial data collection and analysis. The final sample size was 21.

Recruitment occurred in two ways. One method was to contact leaders within advocacy organizations, service organizations and government requesting their direct involvement (Appendix G). The second method was to ask leaders in advocacy groups, service organizations and government to distribute information about the study to people who would meet the inclusion criteria or who could provide a particular perspective as identified as themes emerged in the data (Appendices G and H). When information was distributed within an organization potential participants either contacted the researcher directly or gave permission for the contact person within the organization to forward their name and contact information to the researcher. All participants provided written

informed consent prior to the interview (Appendix I). All participants received a $10.00 gift card for a local coffee shop as a token of appreciation. In addition, participants who did not participate on work time were given an honorarium of $25.00 to compensate them for their time to take part in the interview.

A total of 21 people participated in key informant interviews. Informants completed a participant background information form (Appendix J) to provide a description of the sample. Five (5) informants were between the ages of 21 and 35 years, 6 were between the ages of 36 and 50 and the remaining 10 were between the ages of 51 and 65. Thirteen (13) informants were women.

Participants were recruited on the basis of their affiliation with one of the following groups: five (5) were recruited from advocacy organizations with an interest in mental health and housing policy (advocacy representatives), six (6) were people who need mental health and housing services (citizen-users), four (4) were elected and bureaucrat officials at various levels in government, and six (6) were service providers from a variety of organizations providing services to people with mental health and housing needs. When asked to identify their involvement in mental health and housing policy some participants identified both primary and secondary roles. Table 1 lists the groups from which participants were recruited, the roles participants identified, and the amount of involvement they reported having with mental health and housing policy.

Table 1: Type and Amount of Involvement of Key Informants

Group from which the Key Informant was Recruited	Type of Involvement-Primary	Type of Involvement-Secondary	Amount of Involvement
Advocacy	Advocacy		Quite a bit
Advocacy	Service provider	Advocacy	Quite a bit
Advocacy	Advocacy		Quite a bit
Advocacy	Advocacy		Quite a bit
Advocacy	Advocacy		Some
Client	Client	Advocacy	Quite a bit
Client	Client		Quite a bit
Client	Client		Very little
Client	Client	Service provider	Some
Client	Client	Advocacy	Very little
Client	Client		Some to quite a bit
Government	Government		A lot
Government	Government		A lot
Government	Government		Some
Government	Government		Some
Service provider	Service provider		Some
Service provider	Service provider		Quite a bit
Service provider	Service provider	Advocacy	Quite a bit
Service provider	Service provider		Quite a bit
Service provider	Service provider		Very little
Service provider	Service provider		Some

Interviews

All interviews were conducted by the researcher and occurred during the time period of September to December 2008. A semi-structured interview guide was developed prior to the first interview and modified slightly during the course of data collection to capture new issues and ideas that key informants raised. The interview guide is included in Appendix K. In one case, an informant had a specific expertise and involvement in policy development so an unstructured interview approach was used. Identifying the specifics of the expertise or involvement could identify the individual to others in the policy network so these factors will not be reported here.

Participants were given their choice about the location of the interview. For 13 informants, interviews were done in private rooms at their workplaces. For 6 informants, the interview was done in a private room at a community agency. In one case the interview was done in a room at the researcher's workplace and one interview was done over the telephone. Interviews lasted between 40 and 100 minutes. The length of interview depended on the extent of informants' previous experiences with citizen-user participation in policy development and their communication styles.

Documentation Review

Documents can provide a rich source of information for case studies. Documents can include information owned by organizations such correspondence, budgets, organizational charts, organizational policies, evaluation reports, committee terms of reference and agendas and minutes of meetings. Documents can also include information in the public domain such as news releases, media reports, publicly accessible research

and evaluation reports and annual reports of public institutions. Official documents from agencies and public institutions can reveal the ways that these institutions legitimate their decisions and actions (Silverman, 2001).

All documents reviewed for the study were available in the public domain. The rationale for choosing each document is summarized in Appendix L. Only sections relevant to mental health and housing or sections dealing with citizen-user involvement and applicable to the Manitoba policy context were analyzed in detail. The following documents were reviewed:

- Canadian Collaborative Mental Health Initiative Final Evaluation
- Canadian Collaborative Mental Health Initiative Provincial Consultation Final Report
- Canadian Mental Health Association Winnipeg Housing Task Force Final Report
- Canadian Mental Health Association National Backgrounder on Housing and Mental Illness
- From Knowledge to Action (June 2008)
- Housing and Supports for People with Mental Illness: Provincial Advisory Committee on Mental Health Housing and Related Support Services (June 2008)
- Manitoba Health Consumer Participation in Mental Health Services Planning, Implementation and Evaluation (policy) (2003)
- Mental Health Commission of Canada Research Demonstration Project (September 2008)

- Winnipeg Regional Health Authority Mental Health Advisory Council Report 2005-2006

- Winnipeg Regional Health Authority Mental Health Advisory Council Report 2006-2007

Field Notes

Reflective field notes assist to integrate data collection and analysis which is important in theory building processes (Eisenhardt, 2002). Field notes can stimulate reflection by recording what the researcher is learning as the study progresses (Eisenhardt, 2002).

The researcher maintained reflective field notes throughout the study. Notes were kept in three forms. First, the researcher wrote a reflective field note after every key informant interview. These field notes documented the time and place of the interview, comments on communication, the researcher's overall impressions and interpretations of the interview. Second, the researcher documented an audit trail that described the process of recruitment, data analysis and interpretations. The notes reflected the researcher's decision making through these processes. Finally, the researcher kept a narrative diary of personal reflections throughout the research.

Taken together, these three forms of field notes documented the researcher's personal reflections on how the process of doing the research influenced her thinking about the issue, potential ways that she influenced the research process through her involvement in the research, consistencies and discrepancies in data as it was collected,

and the researcher's decision making processes for data collection and analysis, and alterations to procedures as the study unfolded.

Embedded Case Study

An initial intent of the proposed research was to identify an embedded case study to focus the line of inquiry and facilitate a more pragmatic, rather than entirely abstract, approach to the case (Yin, 2003). This sub-unit of analysis was expected to be an involvement mechanism, such as advisory committee or community forum that officials convened for the purposes of involving citizen-users in mental health policy development. It was anticipated that the embedded case could emerge during the process of fieldwork. However, attempts to access a forum that met the criteria of facilitating dialogue between citizen-users and government officials were not successful. Government officials reported that they felt that the timing for the initiation of other anticipated forums was not synchronous with the timing of data collection for the thesis project.

Despite this limitation, alternative initiatives were evident prior to, as well as during the case study that served to provide focus and pragmatism to the research. The first initiative was a forum convened for the purposes of exploring the potential of mounting a legal challenge related to mental health and social housing issues. Although the researcher attended the forum, it occurred prior to the initiation of the study. Therefore, prior consent was not obtained so that direct observations of the forum could not be included in the analysis. However, the forum provided guidance for recruitment and interviews of key informants by identifying actors within the policy field and

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important issues that could be explored through interviews. The report from the forum was used in the document analysis.

The second initiative that occurred during the case study was a Request for Proposals sponsored by the Mental Health Commission of Canada related to the implementation of a research project to evaluate the effectiveness of two pre-determined social housing models with the option of adding an additional model. Winnipeg was designated as one of five cities in which the research would take place. The project in Winnipeg was intended to have a focus on Aboriginal people. This initiative also provided guidance for recruitment and lines of questioning with some key informants but the housing needs specifically for Aboriginal people was not a focus for the thesis project. The focus remained on the broader policy field of mental health and social housing.

Data Analysis

Key informant interviews were audio-recorded and transcribed verbatim by professional transcribers. The researcher reviewed and verified transcripts based on her presence in the interview and field notes. NVivo (Version 8) qualitative software was used to manage and code transcripts, write memos, and explore data through queries and modeling.

An inductive qualitative paradigm was used to conduct data analysis. For the semi-structured interviews, an initial coding scheme, based on the key topics of the semi-structured interview guide, was developed. Transcripts were read sequentially. Descriptive and pattern codes and sub-codes were added into the coding scheme as they

emerged through line-by-line review of the transcripts. After initial coding of three transcripts, the coding scheme was discussed with two researchers not involved in the project resulting in revisions to the coding scheme. The next 16 transcripts were analyzed and the initial 3 transcripts reanalyzed using the revised coding scheme.

After analysis of 19 transcripts the coding scheme was reviewed again. This review consisted of reading the text contained in each code and sub-code looking for redundancies and inconsistencies within and between codes. In addition, the coding scheme was compared against the process, outcome and contextual criteria and indicators for citizen-user involvement drawn from the literature and from previous phases of the study. This exercise resulted in revisions to the names, descriptions and content of some codes as well as the reduction of the number of codes and sub-codes by approximately 25% to 153. The final two interviews were coded using the revised coding scheme. No new codes were identified during the analysis of these interviews.

During the course of analysis, consideration was given to comparing responses across the four policy actor groups. Although in some cases this comparison was possible, in most cases such comparison would have reduced the integrity of the findings because the groups were not mutually exclusive. For example, some participants who were citizen-users also identified themselves, secondarily, as representatives of advocacy organizations, and some advocates also identified themselves as service providers. Furthermore, participants had many experiences that they called upon within their narratives suggesting that they had a multiplicity of current policy actor roles, previous roles, or other life roles (such as a parent of someone struggling with mental health and social housing needs) that informed their perspectives. As Parkinson (2003) noted

"persons are not the unified individuals of classical liberal theory but are multi-faceted, with multiple roles and fluid, socially constructed, contextualized identities" (p. 187). He went on to argue that people themselves must decide what identities they choose to emphasize in any deliberative forum. Likewise, Lomas (1997) argued that members of the public enter health care priority setting forums with at least three identities, taxpayer, patient and citizen, each of which may result in a different opinion about priority setting. This multiplicity of identities also permeates the process of constructing research narratives in which people draw from diverse experiences, roles and identities to form and communicate ideas and opinions. Participants in this study were recruited because they belonged to a particular actor group but their responses may have, at any moment, resulted from their own decision to emphasize another role or identity. Thus, although the actor group from which each participant was recruited was identified with their particular narrative, it was not always possible to collectively compare the actor groups because an individual, at any moment, may have been speaking from another perspective.

Documents were read and reread for content related to citizen-user involvement in mental health and housing policymaking. Documents were analyzed using the coding scheme developed from the key informant interviews. They provided historical and contextual understanding of the case.

Throughout the process of analysis, memo writing was used to elaborate assumptions and identify similar and contrasting patterns in the data (Miles & Huberman, 1994). In addition, models were created to explore the relationships between codes. These models were compared with the data, elaborated, and revised. The development of models assisted in the identification of areas of clarity and ambiguity. They enhanced

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understanding of how concepts and relationships between concepts emerged from the data and how the data fit with the concepts and relationships.

The final stage of analysis involved developing major themes. These themes focused on the pathways through which citizen-users' voices enter policy discourses, strategies to enhance the pathways, the potential outcomes of involvement and the contextual factors that influence the pathways, processes and outcomes of involvement.

Trustworthiness

For qualitative enquiry, multiple strategies can be used to increase the quality or trustworthiness of data collection, analysis and interpretation. Stake (1995) identified two strategies that are particularly important for adding rigor to the results of case studies, triangulation and member checking. Additional strategies relevant to this study included researcher reflexivity, development of an audit trail, peer debriefing and collaboration (Creswell & Miller, 2000). These strategies are summarized below.

Triangulation

Triangulation adds rigor to qualitative research by combining multiple investigators, theories, methods and data sources (Denzin, 1978). Denzin described four types of triangulation: investigator, theory, methods and data.

Investigator triangulation can involve having more that one observer collect data. However, presenting the observations and interpretations to other researchers for review can be a valuable alternative (Stake, 1995). In the present study triangulation of investigators occurred through consultation with the thesis advisor about data analysis

and interpretation. In addition, the researcher attended a data analysis workshop in which her preliminary analysis was reviewed by two researchers not involved in the project.

Multiple theories and perspectives are another form of triangulation. Including multiple researchers in the interpretation of results automatically incorporates multiple perspectives (Stake, 1995). However, more complex incorporation of multiple perspectives can include interpretations from researchers with a variety of disciplinary perspectives about the same data. In the current study, triangulation of theories and perspectives was facilitated through consultation with thesis committee members who have backgrounds in the disciplines of anthropology, psychology, social work and occupational therapy.

Multiple methods are used to diversify the information from which interpretations are made. Although Patton (2002) interprets multiple methods as combining quantitative and qualitative methods, multiple methods can be used within a qualitative paradigm (Dezdin, 1978). For example, case studies frequently use multiple methods including interviews, observations and document review and these multiple methods help to illuminate the complexity of a particular phenomenon (Stake, 1995). In this study, data collection included key informant interviews and review of relevant documents.

Data triangulation involves comparing the consistency of the phenomenon across various sources of information that may vary according to person, place or time (Stake, 1995). This can be accomplished by strategies such as comparing the perspectives of multiple participants (Creswell & Miller, 2000). In the present study, perspectives were

obtained from multiple individuals within four policy actor groups. Data analysis

included comparing perspectives of the participants within and between these groups.

Member checking

Member checking can be an important component of qualitative research and

involves the processes of returning to participants for confirmation of the credibility of

the data and interpretations of the researchers (Creswell & Miller, 2000). Member checks

can involve returning interview transcripts to participants to ask them to check for

accuracy. Alternatively, reports at various stages of analysis and interpretation can be

provided to participants to obtain their feedback about the interpretation of the findings

(Creswell & Miller). In the present study, member checking was accomplished by writing

a plain language preliminary summary of the findings, mailing it to key informants and

giving them the opportunity to respond via, mail, phone or e-mail. Twenty (20) reports

were mailed; one (1) participant could not be contacted. Two (2) respondents provided

feedback, one (1) by e-mail and one (1) by phone. Suggestions were incorporated into the

final interpretations and recommendations although few suggestions were made. The

modest response to the request for feedback was a limitation of the member checking

process. The purpose of the process was to give people an opportunity to comment or add

additional information rather than to actively solicit more dialogue about the findings.

Instead, meetings with a four member Community Advisory Group for the project served

to engage more active discussion about the findings, interpretations and

recommendations.

Researcher Reflexivity

Researchers bring their own experiences, beliefs and values into the research process. Researcher reflexivity is the self-disclosure of the researcher's assumptions, beliefs and biases (Creswell & Miller, 2000, p. 127). This reflection allows the researcher to explore how prior and current experiences and beliefs may influence the collection, analysis and interpretation of data. This information also allows the users of the research to establish the credibility of the researcher (Patton, 2002).

Reflexivity also refers to the ways in which the researcher is influenced by, and influences the research (Fontana & Prokos, 2007). In this regard, data collection methods such as interviews are seen as discourses that involve negotiated storytelling between the researcher and the research participant. Reflexivity can assist the researcher and others in understanding how their ideas and approaches may have impacted the interpretations and outcomes of the study. In this study the researcher maintained a reflexive field diary. A summary of the researcher's reflections on the research can be found in Chapter 12.

Audit Trail

An audit trail is used to establish the credibility of the researcher's decisions and actions made throughout the research process (Creswell & Miller, 2000). Decisions and actions can include issues such as who is recruited and how many participants, the nature of the interview questioning, the choice of embedded case study, the type and number of documents reviewed, the identification of themes from the analysis, the timing of member checks. An audit trail allows an external person to review the procedures used during the study and determine whether they follow accepted practices and the extent to

which the data and interpretations are confirmable (Guba & Lincoln, 1989). Audit trails are commonly established through researcher journaling and memoing, keeping a research log and recording data analysis procedures (Creswell & Miller, 2000, p. 128). The researcher maintained an audit trail throughout the study documenting activities and decisions.

Collaboration

Creswell and Miller (2000) argued that collaboration with research participants can enhance credibility of the study and prevent marginalization of the population being studied. This collaboration can take the form of a research partnership or less formal arrangements involving advice and feedback. For this research, a Community Advisory Group was established to facilitate collaboration. This committee consisted of four members: two were leaders of mental health related advocacy organizations, one a senior decision maker in a service delivery organization, and one a government employee at the time of initiation of the study. This committee provided advice about lines of inquiry within the broad research questions and feedback about the findings and researchers' interpretations of the findings. The committee also reviewed a draft of the conclusions and recommendations for the study and provided specific suggestions particularly related to focusing on action strategies for addressing issues of social exclusion. These suggestions have been incorporated into the final version of the thesis.

Knowledge Translation

Knowledge translation of the research results was an important consideration in this study. The Canadian Institutes of Health Research (CIHR) (2005) defined knowledge translation as follows:

> Knowledge translation is the exchange, synthesis and ethically-sound application of knowledge - within a complex system of interactions among researchers and users - to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system

Lavis and colleagues (2003) provided a useful framework for organizing ways to disseminate knowledge. They suggested addressing five issues of importance to knowledge dissemination through five questions that could guide the development and implementation of strategies: what should be transferred to decision makers, to whom should research knowledge be transferred, by whom should research knowledge be transferred, how should research knowledge be transferred and with what effect should research knowledge be transferred (Lavis et al., 2003, p. 222).

This framework provided guidance for knowledge translation activities throughout the study. Table 2 summarizes the knowledge translation activities implemented within the scope of this study using CIHR's (2005) framework for opportunities for knowledge translation within the research cycle.

Table 2. Knowledge Translation Strategies

Points in the Research Cycle	Strategies Implemented during the Research
1. Defining questions and methodologies	• Met with stakeholders. • Convened a Community Advisory Group composed of representatives of advocacy, service delivery and government organizations. The committee had input into the processes of the research, interpretations of the findings and development of strategies for disseminating findings. • Attended public forums related to the research topic to develop relationships with key stakeholders and learn about relevant issues, current knowledge and socio-cultural norms.
2. Conducting research	• Met with the Community Advisory Group to discuss findings and preliminary interpretations. • Noted the important issues and norms of various stakeholders that may impact on the exchange of knowledge generated from the research.
3. Publishing research findings	• Disseminated a plain language summary of findings to participants. • Engaged the stakeholder group in the development of recommendations. • Presented preliminary findings in poster presentations at two conferences.
4. Placing research findings in the context of other knowledge and socio-cultural norms	• Explored the ways that the research findings were consistent or inconsistent with other knowledge and norms in discussion of the thesis findings and in the development of manuscripts to be submitted for publication.

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Chapter 6: Introduction to the Findings

This chapter will provide an introduction to the findings of the research. In qualitative research, research questions can be generated from the literature and the researcher's personal experience and assumptions. However, the qualitative researcher does not assume that he or she has the best questions. As the research evolves, assumptions can be challenged and the researcher needs to maintain flexibility to respond to the ideas and priorities of participants. As Creswell (1998) noted, "questions change during the process of research to reflect an increased understanding of the problem" (p. 19). Such was the case with this research. Although the overriding purpose and design remained consistent throughout the research, two of the research questions identified through the literature review were not salient topics for participants. Instead, related but different questions evolved and produced findings more salient to the case study. Thus, I will begin this introductory chapter with discussion and explanations of how the research questions evolved during the course of the study. Next, I will provide context for the findings described in subsequent chapters by giving an overview of the "case" used as the focal point for exploration of citizen-user involvement in policy development.

Evolution of the Research Questions and the Findings

Prior to data collection and analysis, four research questions were identified:

1. How is citizen-user involvement conceptualized by citizen-users and officials (bureaucrats and elected)?

2. How are officials and citizen-users symbolically represented by each other? How do the symbolic representations of officials and citizen-users influence the implementation of citizen user involvement?

3. How are the outcomes of citizen-user involvement conceptualized by citizen-users and officials?

4. How do the contextual elements of citizen-user involvement impact the implementation and anticipated outcomes of citizen-user involvement?

Through the process of conducting key informant interviews, examining documents, and reflecting on, and analyzing data, the first and second research questions evolved.

Initial interviews with citizen-users presented an intriguing alternative to the first research question about how citizen user involvement is conceptualized by citizen-users and officials. A more salient issue that became evident from these interviews was the exploration of the pathways through which citizen-users' voices reach decision makers to inform policy. Much of the literature in the area of citizen involvement in policy development has focused on the examination of discrete involvement mechanisms. These mechanisms have, or should have, clear and relatively short pathways. For, example several key informants spoke about their experiences sitting on an advisory committee which developed a report that was submitted to relevant government ministers. However, key informants also spoke about involvement in multiple other ways, including informal pathways in which citizen-users' voices were translated by others. This line of questioning was pursued in subsequent interviews and the importance of this topic was borne out by inductive data analysis. Therefore, rather than exploring how citizen-users and officials conceptualized citizen-user involvement, data collection and analysis suggested an alternative question: i.e., what are the pathways through which the experiential knowledge of citizen-users enters policy process how can these pathways be strengthened? The findings related to this topic will be reported in Chapter 9.

The second research question, related to the symbolic representations of citizen-users and officials, did not emerge as a fruitful line of questioning in key informant interviews or in the development of themes in the analysis. Instead, the salient theme that emerged for this case study involved the socially constructed representations of citizen-users in a wider socio-political context. This theme became a cross-cutting issue in exploring the outcomes, pathways and contexts of citizen-user involvement in policy development. Therefore, Chapters 7, 9 and 11, describing findings in these areas, will address symbolic representations of citizen-users and how these representations impact on involvement.

The final two research questions, one related to the outcomes of involvement and the other related to the contextual element of involvement, generated findings that expanded on previous literature in the field. Exploration of these two questions has expanded on previous research by exploring outcomes and context in relation to involvement of a population that has been socially and politically marginalized (Standing Senate Committee on Social Affairs, Science and Technology, 2006). In both cases the findings and subsequent interpretations yielded conceptual frameworks that can guide future research and evaluation of citizen-user involvement. The outcomes of involvement will be discussed in Chapter 7 and the contextual elements of involvement in Chapter 11.

The Case

The case study of mental health and housing policy in Winnipeg, Manitoba was a contentious issue throughout the time of the study. Policy activity was evident on several fronts preceding, during and after the data collection stage of the project. In this section I

will highlight relevant policy activity related to mental health and housing. This overview is not meant to be exhaustive but rather to give a flavour of the issues and policy activities that surrounded this policy area.

Organizations providing advocacy for people's mental health concerns had been advocating for better housing for people with mental illness for many years. The Canadian Mental Health Association (CMHA) - Winnipeg Region noted in its 2006 Housing Think Tank Report that its Board of Directors had decided to advocate for decent housing for people with mental illness as far back as 2001. Since that time they had engaged in multiple activities to raise awareness of housing both with government representatives and the public (CMHA – Winnipeg, 2006).

In 2003, Winnipeg Regional Health Authority (WRHA) developed a discussion paper related to the development of a mental health housing strategy. Although not the first discussion paper on mental health and housing, this paper was written by the major provider of publicly funded health services for people with extensive mental health needs in Winnipeg. It marked the intent to re-orientate housing for people with mental health needs from one based on custodial care to one based on supported and supportive housing (WRHA, 2003, p. 7). The housing strategy document identified the desire for a philosophical policy shift from traditional service delivery models for people with mental health and housing needs to a system based on values of enhancing recovery. In 2007, the WRHA's Mental Health Advisory Council also identified housing as an important issue and identified multiple issues within and outside WRHA's health mandate, including the need for access to safe, clean and affordable housing, addressing the needs of individuals, giving people choice over housing and integration of housing within communities

(WRHA, 2007). Thus, over several years the WRHA signaled the need for policy attention to the issues of mental health and housing while also recognizing that the policy issues were broader than its health mandate. This view of the issues of mental health and housing policy crossing jurisdictional boundaries supports the approach used in this case study for examining a policy field rather than a specific policy event.

The Manitoba Government also signaled policy attention to the issue of mental health and housing in 2007. The Cross Department Coordination Initiative (CDCI) was created as a partnership of the Manitoba Government Divisions of Family Services and Housing, and Mental Health and Healthy Living, along with the Winnipeg Regional Health Authority. The mandate of CDCI was to improve coordination of housing related policies and services (Thompson, 2008). Included in the initial focus were people who were homeless and those with mental health issues. The CDCI also made commitments to support the Mental Health Commission of Canada's (n.d.) housing research demonstration project. This demonstration project chose Winnipeg as one of its research sites.

The second initiative of the Manitoba Government was convening the Provincial Advisory Committee on Mental Health Housing and Related Support Services (PACMHH). The mandate of this committee was to review information from the literature and practices in other jurisdictions to create a position paper that would "inform the development of a policy framework on housing and supports for individuals with a mental health disability who require supports and services to obtain and maintain housing" (PACMHH, 2008). This committee's report identified actions required in the areas of housing and supports and challenges inherent in developing a range of housing

options and supports for people living with mental illness. They also acknowledged the special challenges of implementing supports for people with concurrent addictions and for those from First Nations' communities. The committee proposed "considerations" (p. 17) for actions that would improve housing and supports for people living with mental illness, interestingly, not using the term "recommendations". These "considerations' included the development of a variety of housing and supports, funding to address the need for supports, a portable rental subsidy tied to individuals and considerations to address inter-sectoral and inter-jurisdictional issues in collaboration with First Nations.

The "policy problem" related to mental health and housing was summarized in a document published as the result of a June 2008 forum sponsored by the Public Interest Law Centre of Legal Aid Manitoba, the Manitoba Schizophrenia Society and the CMHA - Winnipeg Region (Legal Aid Manitoba et al., 2008). The forum was attended by over 90 participants with diverse backgrounds including representatives of community organizations, service providers and clients. The focus was to share information about housing issues for low income people living with mental health difficulties in Winnipeg and develop an action plan for addressing these issues. Among the issues identified were:

- Prejudice and stigmatization toward people with mental health issues
- People living in unsafe and poor quality housing
- Lack of choice in housing including the range of housing options and low vacancy rates
- Inadequate supports in general and lack of supports appropriate for specific populations such as aboriginal people

- Inadequate shelter allowances (i.e., the employment and income assistance shelter allowance is well below the average rental fee for a bachelor suite in Winnipeg)

- Lack of coordination among levels of government

Forum participants recognized access to safe, secure and affordable housing as a right. In addition, participants noted the importance of involving all stakeholders, including citizen-users, to address housing issues faced by people with mental health and housing needs (Legal Aid Manitoba et al., 2008).

Thus, the need for policy change has been well documented in Winnipeg and Manitoba. Similar concerns have been raised in other provinces (e.g., Patterson, Somers, McIntosh, Shiell, & Frankish, 2008; Sylvestre, George, Aubry, Durbin, Nelson & Trainor, 2007). Federally, the Homelessness Partnership Initiative (Human Resources and Skills Development Canada, 2008) is one example of the Government of Canada's policy attention to issues of homelessness over the past few years. The Mental Health Commission of Canada (n.d.) has taken leadership for a research demonstration project that will evaluate the effectiveness of a Housing First (Tsemberis, Gulcur, & Nakae, 2004) model of service delivery with funding allocated from the federal government and has required the inclusion of consumers in advisory committees (Mental Health Commission of Canada, 2008).

This summary of policy activity has demonstrated the local, provincial and national attention to mental health and housing issues and the nature of the problem that policy change is hoping to resolve. Within this context, the present research was concerned with the ways that citizen-users participate in policy development. Although

activity in other provincial jurisdictions and funding stimulus from the federal

government can influence provincial government policy, the provincial government has

primary responsibility for health and social services within the Canadian Constitution.

Therefore, the question arises as to what the provincial government has done to involve

citizen-users in policy development related to mental health and housing.

Citizen-user Involvement Related to the Policy Issue

In a policy document called *Consumer Participation in Mental Health Service

Planning, Implementation and Evaluation* (Manitoba Health, 2003) the Manitoba

Government stated its commitment to include consumers in mental health service

development (Manitoba Health, 2003). One recent example of such involvement was the

Provincial Advisory Committee on Mental Health Housing and Related Support Services

(2008). This committee was established prior to the initiation of the present study but is

instructive in relation to a process of involving citizen-users. Of the 17 committee

members only one was identified as a "consumer". Two were identified as family

members and one a First Nation representative. The remaining members were

representatives of government departments, provincial regional health authorities and

other service providers. The need to have at least two citizen-users on committees to

address power imbalances has been identified by other research (McDaid, 2009). Not

doing so leaves the government open to concerns about tokenism. This committee is not

necessarily the only initiative that the government has taken to involve consumers but

any other recent examples are not readily apparent. The committee illustrates the ongoing

use of a mechanism that leaves consumers with little power or support from other

consumers in environments intended to contribute ideas to policy development. This has

occurred despite official policy statements mandating consumer involvement. The

development of a consensus set of "considerations" from this committee is laudable.

Subsequent government announcements suggested uptake of some of this committee's

recommendations (Province of Manitoba, 2009). However, to my knowledge, no

evaluation of the committee process was ever undertaken. Without evaluation, it is

difficult to understand the points of disagreement or dynamics of power relationships.

Consequently, it is difficult to determine whether the government did achieve its policy

goal (Manitoba Health, 2003) of involvement over and above the inclusion of a

"consumer" on the committee.

The issues explored in the succeeding chapters of this section will help to

illuminate key issues that can contribute to our understanding of citizen-user

involvement, not only for formal mechanisms such as the example cited above, but also

across the multiple pathways through which citizen-users' experiential knowledge can

reach decision makers. The example of the committee described above illustrates the

need to examine citizen-user involvement across the policy field of mental health and

housing since both the policy issues and proposed solutions are beyond the scope of a

single involvement mechanisms and cross multiple jurisdictional boundaries.

Development of the Model

The purpose of this research was to develop a framework that can facilitate the

development and evaluation of citizen-user involvement in policymaking. The model

consists of four major components. My previous research identified the characteristics of

the processes of involvement mechanisms that are valued by citizen-users. This research

obtained the perspectives of actors within the policy network about the potential

outcomes, the pathways to involvement and the contextual factors that influence

involvement. The subsequent chapters will serve to build the model based on the findings

of this research.

I begin in Chapter 7 with findings related to the outcomes of citizen-user

involvement. Outcomes provide important guideposts for the rationale of involving

citizen-users and suggest evaluation questions and criteria for mechanisms intended to

include them. Chapter 9 will describe findings related to the diverse pathways of

involvement and issues surrounding the integrity of the pathways. In Chapter 11, the

contextual factors that influence the processes and outcomes of citizen-user involvement

are discussed. Exploration of the contextual factors can increase understanding of the

forces that support or inhibit involvement and courses of action that can modify context

to facilitate more effective pathways. Chapter 12 includes researcher reflections and

limitations of the study. Finally, I present the overall model for citizen-user participation,

recommendations, and directions for future research.

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Chapter 7

Risk and reward: Defining the outcomes of citizen-user involvement in mental health policymaking

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Introduction

The importance of involving citizens in social policymaking has been recognized by federal, provincial and territorial governments in Canada (Government of Canada, 1999). This involvement is believed to enhance both the quality and transparency of decision making (Organization for Economic Co-operation and Development (OECD), 2001) and to hold the levels of government accountable for their decisions (Phillips, 2001).

People who use and need mental health and housing services (citizen-users) require sound public policy because of their experiences with illness and poverty. Yet these people are often excluded from policy debates due to structural and procedural barriers inherent in many of the mechanisms created to involve citizens (Barnes, 2002).

The findings reported here were derived from a qualitative study that explored the involvement of citizen-users in the development of health and social policy. These findings identify potential outcomes of involvement with the aim of developing a framework that could be used to evaluate the effectiveness of involvement processes.

Literature Review

The involvement of citizens in policymaking related to health services, including mental health services, has not been evaluated extensively. Systematic reviews (Crawford et al., 2002; Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006) have uncovered few articles that report on the effectiveness of participation even when the scope of the search for relevant literature was broad. In a recent scoping review of public involvement in developing health care priorities, Mitton and colleagues (2009) concluded that evaluation

is rarely reported and is more likely to emphasize processes than outcomes. In addition, evaluations often focus on discrete involvement mechanisms such as Citizen Juries (e.g., Davies, Wetherell & Barnett, 2006) limiting generalizability to other mechanisms and contexts.

Conclusions that can be drawn about outcomes of involvement in health policy are unclear. In one notable controlled trial on public involvement in goal setting, Abelson, Eyles, McLeod, Collins, McMullen and Forest (2003) found that deliberation can impact on participants' opinions. From their systematic review of involving patients in health care planning, Crawford et al. (2002) concluded that involvement could result in changes to services but other impacts on service quality were not clear.

In relation to citizen-user involvement in mental health policy, the accumulated outcome literature is even more lacking. Instead, a more common focus of research has been to identify the structures and processes that can be used to involve people who use mental health services in service development (e.g., Restall & Strutt, 2008) and the impact of partnerships with citizen-users in participatory action research (e.g., Ochocka, Janzen, & Nelson, 2002). Furthermore, there is no model providing guidance as to what outcomes should be evaluated when determining the impact of citizen-user involvement in policymaking.

Outcomes of Involvement

One approach to identifying outcomes is to consider arguments about the benefits that governments and society hope to achieve by engaging citizens more actively in policy decisions. Arguments for involvement include social benefits which can be

categorized as substantive, instrumental and normative (Beierle & Cayford, 2002; Fiorino, 1990). In addition, there may be personal benefits for the people who participate in mechanisms that facilitate involvement (e.g., Crawford et al., 2002).

Substantive arguments for involvement claim that citizen involvement results in better policies and services (Barnes, Newman, Knops, & Sullivan, 2003; Beierle & Cayford, 2002; Coney et al., 2004; Fiorino; 1990). Citizen involvement should also advance the long term goals of the health system to improve the health status of populations (Thurston et al., 2005) with better use of resources and increased efficiency of services (Coney et al., 2004).

Normative arguments for participation claim that participation in public policy development is a right of people who are affected by the decisions (Beierle & Cayford, 2002; Fiorino; 1990). Participation is believed to promote a stronger democracy (Barnes et al., 2003; Gauvin & Abelson, 2006; OECD, 2001) and address issues such as social exclusion (Barnes, 2002). The Canadian Collaborative Mental Health Initiative (2006) supports citizen-users' rights to be fully involved in their own recovery including participation in policymaking.

Instrumental arguments claim that involvement of citizens will increase legitimacy of policy decisions (e.g., Barnes et al., 2003; Beierle & Cayford, 2002; Gauvin & Abelson, 2006). Citizen involvement may decrease conflicts among policy actors and groups (Beierle & Cayford, 2002) improving relationships within communities (Farrell, 2004). Involvement may enhance the capacity of communities to respond to health issues

through the development of new organizational structures, leaders and other resources

that may have longer term impacts (Phillips & Orcini, 2002; Thurston et al., 2005).

In addition to social benefits, involvement in policy development may have

personal benefits to participants. Benefits to citizens may accrue through increases in self

esteem (Crawford et al., 2002), people finding and recognizing their own strengths

(Barnes & Shardlow, 1997), greater empowerment (Consumer Focus Collaboration,

2001) and participants perceiving benefits through increased knowledge and social

connections (Delli Carpini, Cook, & Jacobs, 2004; McIver, 1998). Officials may increase

the skills with which they can engage the public over time (McIver, 1998).

Mental Health and Social Housing Policy

The link between the need for good social housing policy and the challenges

faced by people with severe and persistent mental illness have been well established

(Canadian Institute for Health Information (CIHI), 2007; Dunn, 2002; Standing Senate

Committee on Social Affairs, Science and Technology (SSC), 2006). People who

experience mental illness frequently report concerns about difficulties accessing safe and

affordable housing (SSC, 2006) and are often over represented in groups who are

homeless (CIHI, 2007). Likewise, poor housing conditions can negatively affect the

health and well-being of people with mental illness (Dunn, 2002). Despite a few

examples in Canada of mental health service users being involved in reorganization of

housing services (e.g., Lord, Ochocka, Czarny, & MacGillivary, 1998), there has been

little documentation of citizen-user involvement in policymaking related to housing.

Increased understanding of the outcomes of involvement, both risks and rewards, can provide a basis for developing more effective processes to engage people with mental health and housing needs who are often excluded from social and political life. This paper reports on how the potential outcomes of citizen-user involvement in mental health policy are conceptualized by policy actors and proposes a framework to guide future outcome evaluation of involvement mechanisms.

Methods

Design

The study used qualitative instrumental case study methodology (Stake, 2005). Policy activity at the time of the study in the province of Manitoba suggested that the issue of mental health and social housing was on the provincial government agenda and could provide a backdrop for understanding the involvement of people who use mental health services in policy development and the potential outcomes of involvement. Rather than study a particular policy activity, the larger policy field provided a "case" that yielded opportunities in both sampling and data collection to expand the context from which citizen-user involvement could be explored.

Data Collection

Key informant interviews. Following Flick's (2006) approach to theoretical sampling, four groups were defined *a priori* because they were expected to have differing perspectives of the issues under study. The sampling frame consisted of key informants from each of the following policy actor groups: citizen-users, representatives of advocacy organizations, government officials (elected representatives and bureaucrats), and service

providers. From among these groups, initial participant selection was based on the criteria

that informants were involved in policy debates related to mental health and housing in

Manitoba. It is important to note that, although participants were recruited from these

groups, they were not mutually exclusive and some participants identified themselves in

more than one group. Recruitment occurred in two ways. One method was to contact

leaders within advocacy organizations, service organizations and government requesting

their direct involvement. The second method was to ask leaders in advocacy groups,

service organizations and government to distribute information about the study to people

who would meet the inclusion criteria or who could provide a particular perspective as

identified by themes as they emerged in the data. All participants provided written

informed consent prior to the interview. The study was approved by the Research Ethics

Board at the University of Manitoba.

Twenty-one (21) participants were recruited on the basis of their affiliation with

one of the policy actor groups: citizen-users (n=6), representatives of advocacy

organizations (n=5), government officials (elected and bureaucrats) (n=4), and service

providers (n=6). Five (5) informants were between the ages of 21 and 35 years, 6 were

between the ages of 36 and 50 and the remaining 10 were between the ages of 51 and 65.

Thirteen (13) informants were women.

The majority of key informants were interviewed using a semi-structured

interview guide that asked questions about their experiences with health and social policy

debates and their perspectives about the purposes and contexts of citizen-user

involvement. An unstructured approach was used to interview one key informant who

had a particular perspective on the policy area.

Document review. Documents reviewed for the study included government policies on consumer participation, initiatives related to mental health and social housing, and reports from contemporary forums that included dialogue with citizen-users about mental health and housing policy.

Field notes. The researcher maintained reflective field notes after every interview and during the process of conducting data analysis. The notes assisted with integrating data collection and analysis and provided an audit trail detailing the researcher's decision making throughout the research process.

Data Analysis

Key informant interviews were audio-recorded and transcribed verbatim. NVivo (Version 8) qualitative software was used to manage and code transcripts, write memos, and explore data through queries and modeling.

An inductive paradigm modeled after methods described by Miles and Huberman (1994) was used in data analysis. An initial coding scheme was developed from the key topics in the semi-structured interview. Descriptive and pattern codes and sub-codes were added into the coding scheme as they emerged through line-by-line review of the transcripts. After initial coding of three transcripts, the coding scheme was discussed with two researchers not involved in the project resulting in revisions to the coding scheme. The transcripts were reanalyzed using the revised coding scheme. After analysis of 19 transcripts, the coding scheme was revised by reading the text contained in each code and sub-code looking for redundancies and inconsistencies within and between codes. The final two interviews were coded using the revised coding scheme. No new codes were

identified during the analysis of these final interviews suggesting theoretical saturation of the data based on the sample. As a member checking procedure, participants were mailed a summary report of the findings and given an opportunity to respond in writing or by phone. Themes related to the expected outcomes of involvement are reported here.

Findings

A review of a broad range of literature suggested that positive outcomes of citizen-user involvement could occur within four distinct and interrelated categories: substantive, instrumental, normative and personal. The findings of this research provided a descriptive application and validation of the categories for these categories related to citizen-user involvement in mental health and housing policy development. Although the categories were derived *a priori* from the anticipated benefits of involvement, the results of this study indicated that they were double-edged; key informants identified both positive and negative outcomes. Informants were cognizant of the potential risks and rewards of involvement.

Substantive Outcomes

Substantive outcomes pertain to the meaningful and important ends of public policy. Key informants from all four of the policy network groups emphasized the importance of achieving policy goals that make services and life better for those with mental health and housing needs. Consistent with local government rationale for involvement in service planning (Manitoba Health, 2003) informants noted that involving citizen-users increased the likelihood that policies and services would improve. Citizen-user perspectives could describe how policies benefit or create barriers for citizen-users

and increase the acceptability and effectiveness of supports and services. One service provider noted that not including citizen-users was a gamble:

> ... if you want to have an impact that's effective in terms of service delivery and creating support services and programs that are going to work for people with mental health issues and people that are homeless, then you have no choice but to include them in the process because otherwise it's like throwing the dice. It may work. It may not work. You're, you're just taking a risk right without really having the people whose lives have been affected and impacted …. They know … what's worked in the past for them and what didn't work and they can bring that experience.

This quote emphasizes the experiential and contextual knowledge that citizen-users bring to policy discourse. Klein (2000) claimed that, because of its highly contextual implementation, policy is an experiment of what works and what doesn't. Citizen-users can minimize the experimental policy gamble by contributing experiential knowledge about what could work.

Although achieving the goals of policy to improve programs and services has had almost universal acceptance in terms of an expected outcome of citizen-user involvement, the greater challenge is articulating the goal of the policy. In the case of mental health and housing policy, the goal may be to ensure that each person with mental health and housing needs is adequately housed, or that a sub-group of people with these needs are housed. However, competing goals of other stakeholders may compete for budget attention. The issue of goal clarity was illustrated by one service provider who was

discussing the implementation of the Housing First model (Tsemberis, Gulcur, Nakae, 2004), which the Manitoba Government, along with the Mental Health Commission of Canada was developing a strategy for implementation in Manitoba at the time of the study. This key informant noted that the potential success of the model was based on the focus on the goal of getting everyone a place to live and stated, "that simplicity…and that focus on a singular outcome … is really important to the success." The implication for involvement in mental health policy is that, if the policy outcome is clear and specific, the outcome will be easier to evaluate and the contribution of citizen-users perspectives to the success of the policy, easier to track.

Normative Outcomes

Normative outcomes pertain to the values and standards of a democratic society. Thus, normative outcomes should include consideration of whether individual citizen-users participate in social and political institutions and whether mechanisms to include their voices create environments that encourage more widespread participation of people with mental health and housing needs.

The importance of normative outcomes for this population was highlighted by many key informants who talked about the multiple barriers to involvement in policy decisions that were grounded in socially constructed attitudes toward people with mental health and housing needs. These attitudes, variously described as stigma, prejudice and discrimination are well documented and appear to be exacerbated by media reports of persons with mental disorders (e.g., Kirby & Keon, 2004). These attitudes impact on

whether people with mental health and housing needs were seen as legitimate contributors to debates about policy. One advocacy representative noted:

> I think that stigma generally in mental health changes the idea of public participation in a way that it doesn't in any other area. I think that there's always a segment of the population that thinks that people with mental health issues are not competent to be a part of decision-making and policymaking .… I think stigma will always play a role in, in how seriously people with lived experiences will be involved in decision making.

Other informants noted that people with mental health and housing needs may experience additional stigma and social exclusion associated with poverty and substance abuse. This triple source of stigma made it socially difficult for people to engage in policymaking.

Stigma was also viewed by some citizen-user, advocacy representative, and service provider informants as making it difficult for governments to implement policy changes. For example, public discourse around those who may be deserving of supports and services and those who are undeserving could make it difficult for government to prioritize mental health and housing issues in the face of other more publicly acceptable policy issues. This may result in "structural discrimination" (Link & Phelan, 2001) so that mental health related programs and services do not receive a share of the public funding in keeping with the burden of illness (Kirby & Keon, 2004).

Instrumental Outcomes

Instrumental outcomes pertain to the means by which citizen-user perspectives are obtained. Key informants emphasized the importance of communication and relationship building as instrumental outcomes that played intermediary roles between citizen-user input and policy decisions.

Many key informants viewed communication as an important outcome of involvement mechanisms. The sharing of perspectives facilitated the contribution of various actors to understanding the issues and proposing solutions. The importance of experiential knowledge was not confined to mental illness and housing; one service provider also noted the importance of bringing an ethno-cultural perspective into policy discourse. Such a perspective can bring greater understanding of the norms and values of groups such as aboriginal peoples that can contribute to an understanding of whether any particular government action is likely to be accepted by a particular group.

Communication was important but not sufficient for many advocacy representatives and citizen-users. These key informants noted that the documentation of communication, such as writing the results of the involvement process through a report, promoted transparency of the process. Tensions could occur if a report was written but not released publicly and the people who participated in the involvement mechanism were bound by confidentiality agreements not to share the findings with their constituents. Thus, formal inclusion of citizen-users and advocacy representatives may be undermined by a lack of transparency about final decision making process.

Although communication was viewed as an important outcome for contributing to policy decisions, it was seen by some participants, from both citizen-user and government official groups, as having symbolic meaning in terms of legitimizing decisions that may have already made. A citizen-user talked about a personal experience in this regard:

> I think that they had an agenda about what they were going to set up and how they were going to set it up… before they even started. To me, it was just more like listen to your stories so they'd have some information from a consumer, but it seemed to me that the higher-ups had made some kind of decision on like the model they wanted to use.

This symbolic use of citizen-user voices may serve to collect horror stories about people's experience in poor housing that could create sympathy for a policy that a government official may have to sell to colleagues and the public. However, it may have a negative impact by creating resentment on the part of participants who questioned the legitimacy of the contribution of the involvement mechanism to the decision making process resulting in disengagement from future policymaking.

Better relationships were viewed by some key informants as important outcomes of dialogue between decision makers and citizen-users or advocacy representatives. Government officials and advocacy representatives may realize a mutual benefit of a positive relationship, one in which advocacy representatives may temper their criticism of government while officials may be more willing to consult with advocacy representatives when the relationship is positive. However, these relationships may make it difficult for advocacy representatives to take a more confrontational approach when necessary. This

was also an issue when the relationship extended to one in which the advocacy representative's organization received funding from the government. Likewise, a government official noted the challenge, in some cases, of making timely decisions when there was an expectation for a power sharing relationship.

Personal Outcomes

Personal outcomes pertain to the impacts on individuals who participate in involvement mechanisms. Key informants noted that the impacts could be positive or negative.

Participants across all four groups talked about personal empowerment of citizen-users as one of the potential positive outcomes of participating in involvement mechanisms. This empowerment could be experienced as feelings of greater self-esteem, confidence and personal satisfaction. From the perspectives of citizen-users this empowerment also appeared to be closely tied to concepts of reciprocity. One citizen-user noted:

> … I've had like so many people over the past years contributing to like helping me out. Now it's finally time to start turning some of that around …. I've been on the receiving end of the spectrum for a long time and now it's time to start getting on the, the other end of the spectrum, the giving end of the spectrum.

From this perspective the exchange was based on a generalized reciprocity where people saw the importance of giving back to society after they had been recipients of social supports and services.

Reciprocity was also evident in the discourse of a government official who spoke about more immediate personal exchanges:

I'm going to use a word that is overused way too much, is that empowerment, but that knowing that somebody in a position that can instill change is listening to them … why I do it is for both of those reasons, because I know the impact of me setting up a meeting with an individual who's a consumer and say I want to hear you and making that time. It helps me do a much better job, but what it does for that person, too.

Although key informants saw the potential for citizen-users to personally benefit from participating in involvement mechanisms, there were also inherent risks of disempowerment. Several citizen-users talked about feelings of vulnerability in participating in forums; the reactions of other participants could make it difficult for them to share their perspective. One citizen-user noted that other participants "can snort at somebody's opinion and, if the person's sensitive, you won't hear from him again."

Frustrations with delays in seeing policy changes can impact on advocacy representatives and service providers. For service providers this may mean that they don't see any results from their attempts to bring an issue forward through bureaucratic channels; for advocacy representatives it may mean frustration with their more direct involvement in government initiated mechanisms to solicit input. One advocacy representative noted:

… people who have been in the field for a long time can attest to the amount of times we've been on a committee, a committee or report that's been shelved and

never seen and it's hard to imagine that you spent that kind of time and put that kind of energy into something that you believed in for it to just essentially become a shelved report.

This quote also suggests the importance of considering the opportunity costs of engaging in government initiated involvement mechanisms. This may be a particular issue for representatives of advocacy groups who have to make very difficult decisions about the best way to influence government policy.

Government officials also experience personal risks in conducting involvement forums. Several noted the risk of setting up expectations that couldn't be met. As one official commented:

We invite citizens in to do that beyond consultation or focus groups or whatever, then you … have to understand that you're giving away some of your power or you're willing to share some of that power and that's problematic. It may take way more time to reach a decision on something, because you have to … reach consensus. You may set up the expectations for people greater than what you can afford; that's always a big fear of government.

This quote reinforces the notion that government officials recognize the multiple contextual factors that influence policymaking. Within Canada's representative democracy, public policy decisions ultimately rest with elected officials. Citizen-user input is just one source of information among multiple inputs. Other inputs include financial constraints and competing priorities from other government decision makers.

Government officials who organize forums may not only feel that unrealized expectation may reflect badly on the government as a whole, but may also feel that a poorly conducted forum could reflect badly on them personally. One official noted:

> … it takes time to set up these sort of processes and … often you'll only have one … shot to do it so if you're not right doing it right the first time …. I guess there's discouragement … for the people who are actually doing it. I know I've been out to things where I was so embarrassed, you know, I can't believe, you know, we made people come out for that.

Discussion

This study developed a framework for evaluating the outcomes of citizen-user participation in policy development. The framework includes the four categories of outcomes: substantive, instrumental, normative and personal. Figure 1 summarizes the outcomes in each of these categories and examples of evaluation questions.

Other researchers have identified criteria for evaluation of public participation. Rowe and Frewer (2005) identified multiple criteria from diverse evaluations of public engagement which were subsequently summarized into 19 criteria by Abelson and Gauvin (2006). Many of these criteria addressed how the participation processes influenced decision making, policy and institutional practices. Criteria also addressed the effect of participation on the public's knowledge, views, values and opinions. This study expands on previous work by addressing inclusion of a population at high risk for poor health outcomes and marginalization from social and political processes. The processes

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used to engage citizen-users should set goals and measure outcomes across all four of these categories.

Substantive outcomes remain the hallmark of citizen-user involvement. Our key informants overwhelmingly identified improving the lives of people with mental health and housing needs as a primary goal of including citizen-users in the policy development process. The challenge is to establish agreement about the specific and measurable goals of the policy and the impact of citizen-user involvement on policy decisions. Evaluation of the citizen-user involvement is complex and it is difficult to unravel the effects of participation from other potential causes and effects (Thurston et al., 2005). Substantive outcomes such as improvement in social housing for people who use mental health services may be distal to the process of involvement. Multiple other contextual factors may influence decisions or stall policy implementation. Despite these challenges, clear articulation of the intended goals of a policy change will facilitate the establishment of the links between involvement and substantive outcomes.

Normative outcomes of enhancing citizenship are often espoused as one of primary reasons for governments to involve citizens in policymaking (e.g., OECD, 2001). Our key informants acknowledged the ways that people with mental health and housing needs were excluded from exercising their power within policymaking. These social barriers are well documented (Kirby & Keon, 2004). The inclusion of people with mental health and housing needs as active participants in policy making can facilitate creative opportunities to address the citizenship rights and responsibilities. Normative values related to the rights of citizen-users to participate in decision making have been stated in documents such as the Manitoba Health's (2003) consumer participation policy; and the

Mental Health Commission of Canada's (2008) request for proposals for research applications for its mental health and homelessness projects. However, these documents do not articulate broader citizenship expectations for enhancing inclusion in social and political processes. Clearer expectations for outcomes aligned with normative values should be a primary consideration of involvement mechanisms with this population.

Instrumental outcomes tend to be associated with the more proximal outcomes of "one-off" involvement mechanisms intended to promote dialogue about the policy issue. These mechanisms can be convened with expectations for various levels of involvement from consultative to a stronger advisory mandate. Our informants suggested that regardless of the level of involvement the outcomes should include communication, transparency of decision making and relationship building. The desire for transparency is consistent with other research related to public engagement in health services (e.g., Teng, Mitton, & MacKenzie, 2007).

Risks for participants can arise when decision makers and citizen-users disagree on the desired outcomes. For example, officials can perceive the legitimization of policy decisions as a positive outcome, whereas citizen-users may perceive their input into a policy decision as a negative token gesture that served the government's goal of a symbolic use of the involvement mechanism to further its own political agenda. The remedy is to make explicit the intended outcomes. Clearly, if the government's intent is to increase the legitimacy of its decisions, then engaging in a process in which people feel abused has not furthered the goal of legitimacy but rather increased the cynicism of participants and the policy network about the intentions of decision makers to share power.

Finally, personal outcomes need to be identified and evaluated in any citizen engagement process. Participants in all four of our policy actor groups spoke directly or indirectly about the vulnerability they have experienced in engaging in involvement mechanisms. These vulnerabilities need to be named and addressed as a comprehensive evaluation of participation in policymaking. Individuals have much to gain and lose within these processes, especially the least powerful. Action can be taken to develop supports for people who engage in these processes. Conveners need to ensure that there is an explicit commitment to manage personal risks and to work to promote inclusive, respectful and flexible processes (Restall & Strutt, 2008).

Although all four dimensions of the framework should be considered in any evaluation of citizen-user involvement, the process of evaluation is complex and limited. Anticipated outcomes may be diverse and not shared by all participants. For example, government may convene a forum with the expectation of an advisory outcome, whereas citizen-user participants may be expecting a decision making outcome. Applying the framework can support dialogue amongst actors about the expected outcomes of any particular involvement mechanism.

Conclusions

This study explored the involvement of people who use mental health and housing services in policymaking. The case study was limited in scope by time, place, population and policy issue. Future research needs to explore the application of the framework to diverse policy activity, populations and policy issues. Sylvestre and colleagues (2007) have observed that most research related to housing for people with complex mental

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health needs has addressed therapeutic values focused on improving the well-being of individuals with less attention to values related to citizenship. Inclusion of citizen-users in policymaking is a citizenship issue requiring evaluation approaches that emphasize participation and social action.

Repeated and urgent calls for greater citizen-user involvement in policymaking illustrate the need for greater understanding of impacts on policy, democratic processes and people. Without a clear understanding of the desired and potential outcomes of citizen-user involvement, involvement processes will continue to be plagued by unmanaged risks, unrealized potential and unknown impacts.

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Figure 1

Outcomes of Citizen-user Involvement in Mental Health Policy Development

Substantive

- Achievement of the policy goal(s)
    - What is the policy goal; what are competing goals for governments?
- Improved health and wellbeing for the population
    - Has involvement resulted in policy decisions that have led to population health improvements?

Normative

- Increased social and political participation of individual citizen-users
    - How many individuals participated in involvement mechanisms; do these individuals continue to be involved in other social and political activities?
- Increased social and political participation of the population
    - Do citizen-users engage more in social and political activities?
    - Are there fewer structural barriers to participation of citizen-users in political life?

Instrumental

- Communication resulting in transparency of decision making processes
    - What communication occurred as a result of the involvement and decision making process?
    - To what extent were citizen-users involved in developing, implementing and evaluating communication strategies?
- Better relationships between policy actors and government
    - Do governments, professionals and citizen-users perceive that they experience better, or worse, relationships?

Personal

- Empowerment of citizen-users
    - Do citizen-users feel more, or less, empowered to influence policy decisions that affect their lives?
- Management of personal risks for all participants
    - Has there been recognition of the potential risks to all participants; have risks been addressed?

Chapter 8: Link to Chapter 9

The previous chapter reported on participants' perspectives about the potential and desired outcomes of citizen-user involvement in policymaking. Although the focus of the case study research was on the policy field of mental health and housing, the outcomes identified through key informant interviews and document reviews and their consistency with other literature, suggest that they are transferable across policy fields. The findings also identified issues that can be particularly salient to citizen-users who can face greater barriers to participation in policymaking than many other groups. The discussion of outcomes addresses the important issue of *why* citizen-user involvement in policymaking is important. Outcomes identified the potential risks, and most importantly, the benefits that should be the primary focus of engagement processes.

The next chapter addresses the issue of *how* the experiential knowledge of citizen-users is engaged in policy discourse. The direct and indirect pathways that this knowledge travels to gain access to policymaking are explored. Key informants provided their perspectives on the strengths and weaknesses of the pathways and strategies to strengthen the integrity of the pathways.

Chapter 9

Pathways to Translating Experiential Knowledge into Mental Health Policy

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Introduction

The need for a mental health services system that promotes the recovery of people living with mental problems has been identified as an important goal for transforming mental health services and supports in Canada (Standing Senate Committee on Social Affairs, Science and Technology (SSC), 2006) and the United States (President's New Freedom Commission on Mental Health, 2003). A recovery oriented system protects the rights of people living with mental illness to have equal opportunities in society and to experience empowerment and self-determination (Anthony, 1993). It facilitates the engagement of people with mental health problems as citizens in social and political life. In addition, participation in program and policy decisions has been identified as a helpful factor for supporting recovery (Onken, Dumont, Ridgway, Dornan, & Ralph, 2006). Thus, involvement in policymaking can be an indicator of successful engagement of people as citizens in a recovery oriented service system as well as a facilitator of personal recovery. Mezzina and colleagues (2006) argued that citizenship may be both a precondition and consequence of recovery.

The findings presented here were drawn from a study that explored how people who need and use mental health services (hereafter called citizen-users) participate in policymaking. The aim was to illuminate the pathways through which the experiential knowledge of citizen-users enters policy discourses using the case example of mental health and housing issues.

Opportunities for Policymaking

Several opportunities for involvement in health and social policymaking are open to citizens in representative democracies such as Canada. Citizens can become elected representatives in governments and can participate in the governance of public institutions through membership on boards of directors. Despite these opportunities, few citizens participate directly in policymaking and those who do participate tend to be clustered descriptively with particular demographic characteristics. For example, Chessie (2009) found that members of Canadian Regional Health Authorities' governance bodies were disproportionately middle-aged and highly educated. Additional opportunities are available to citizen-users for participation in governance bodies of consumer run organizations although the number of organizations is limited.

Accessing Health Policymaking

Despite some formal opportunities for involvement in health policymaking, there is general consensus in the literature that citizen-users face multiple barriers to accessing policymaking processes (e.g., Barnes, 2002). These barriers stem, in part, from the historical context of health policymaking which has been a closed system dominated by professionals and bureaucrats. In the case of mental health policy, Mulvale and colleagues (2007) showed how the organization of mental health services in Ontario emphasized institutionalization and physician policymaking dominance with little public interest.

To attempt to shift decision making processes and promote accountability, Canadian federal and provincial governments have established national and provincial

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commitments to citizen involvement in policymaking (e.g., Government of Canada 1999). In some cases, governments have mandated involvement of citizen-users. For example, the provincial government of Manitoba documented its expectation that Regional Health Authorities include service users in service development (Manitoba Health, 2003). While these commitments promote citizen-user involvement, they are relatively silent on the ways for these expectations to be actualized.

Governments have involved citizen-users through top-down formal mechanisms such as advisory committees and community forums. These mechanisms have received considerable attention in the literature in terms of their purposes and level of decision making (e.g., Rowe & Frewer, 2005). Unfortunately, little attention has been paid to the outcomes (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006). In addition, the ways that these forums are constructed has limited the involvement of citizen-users. For example, standards of behaviour common in the exchanges within committees and forums have not necessarily been those deemed important by all consumer participants (Church, 1996). In addition, many citizen-users lack the resources and supports required to participate.

In addition to forums convened by decision makers, "bottom-up" approaches have been initiated by individuals or representatives of advocacy organizations to gain the attention of decision makers. Bottom-up approaches include, but are not limited to, lobbying and social protest. These approaches can be important opportunities for citizen-users to promote personal recovery and policy change (e.g., Deegan, 1992). Outcomes of bottom up approaches by groups of citizen-users have not been clearly documented. While some important impacts have been attributed to disability related consumer

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organizations, such as the inclusion of equal rights for people with disabilities entrenched in the Canadian Constitution (Dunn, 2002), the influence of these organizations has appeared to have eroded in recent years (McColl & Boyce, 2003). The impacts of these organizations on inclusion and citizenship remain unsatisfactory to many advocates (Prince, 2004).

Citizen-user Experiential Knowledge within Policymaking

There is growing acknowledgement that evidence used for the development of mental health policy should include relevant information derived from the medical and social sciences and from people with lived experience of mental illness (SSC, 2006). However, given the barriers to participation in direct policymaking, how can people who are most vulnerable to the outcomes of health and social policy, such as those who are poor, homeless and have a mental illness, participate in policy decisions? In particular, how is their experiential knowledge of having mental health and housing needs, shared with decision makers?

Objective

The purpose of this research was to explore the involvement of citizen-users in mental health policy decision making. The findings reported here explored the pathways through which the experiential knowledge of citizen-users gains access to policymaking.

Design

Qualitative instrumental case study methodology (Stake, 2005) focused the study on citizen-user involvement in mental health and housing policymaking in the province of Manitoba, Canada. Primary data collection occurred within the City of Winnipeg during the three month period between September and December, 2008. Key informant interviews and documents provided data that situated the case study within a contemporary and historical perspective. The Health Research Ethics Board at the University of Manitoba approved the study. A Community Advisory Group consisting of representatives of the provincial government (1), an RHA (1) and non-profit advocacy organizations (2) provided advice regarding the conceptualization of the project and interpretations of findings.

Data Collection

Key Informant Interviews

Twenty-one (21) key informants were purposively recruited from the following groups: citizen-users (n=6), representative of advocacy organizations (n=5), government officials (including elected representatives and bureaucrats) (n=4), and service providers (n=6). Participant selection was based on the criterion that informants were involved in policy debates related to mental health and housing in the province of Manitoba, Canada. Participants were recruited by contacting leaders within advocacy organizations, service organizations and government to request their direct involvement. In addition, leaders in these organizations were asked to distribute information about the study to people who

met the inclusion criteria. All participants provided written informed consent prior to the interview.

Five (5) informants were between the ages of 21 and 35 years, 6 were between the ages of 36 and 50 and the remaining 10 were between the ages of 51 and 65. Thirteen (13) informants were women.

Interviews were conducted by the first author, in most cases, using a semi-structured interview guide. The guide began by asking participants about their experiences with mental health and housing policy development. Subsequent questions explored the meanings they attributed to citizen-user involvement, how citizen-users have been represented in policy development, purposes of citizen-user involvement and factors influencing involvement. An unstructured approach was used to interview one key informant who had a specific perspective on the policy area. Participants were interviewed in locations convenient to them including private rooms at their workplace, the researcher's workplace, a community agency; one interview was conducted by telephone.

Documents

Documents reviewed for the study included government policies on consumer participation, requests for proposals, forums reports, and relevant documents from advocacy groups.

Data Analysis

Key informant interviews were audio-recorded and transcribed verbatim by professional transcribers. NVivo (Version 8) qualitative software was used to manage and code transcripts, code documents, write memos, and explore data through queries and modeling.

Inductive qualitative methods as described by Miles and Huberman (1994) guided data analysis. An initial coding scheme, based on the key topics of the semi-structured interview guide, was developed by the first author. Codes were added into the scheme as they emerged through line-by-line review of the transcripts. After initial coding of three transcripts, the coding scheme was discussed with two researchers not involved in the project resulting in revisions to the coding scheme. After analysis of 19 transcripts the coding scheme was revised by looking for redundancies and inconsistencies within and between codes. The final two interviews were coded using the revised coding scheme. No new codes were identified during the analysis of these final interviews suggesting theoretical saturation of the data based on the sample. The first author maintained reflective field notes that assisted to integrate data collection and analysis and provided an audit trail detailing decision making throughout the research process.

As a member checking process, key informants were mailed a draft summary of the results and given the opportunity to provide feedback and comments. Feedback was incorporated into subsequent reports.

Results

Policy activity related to mental health and social housing was evident in the jurisdiction throughout the time of the study. Key informants, documents, and public discourses identified concerns about the high prevalence of homelessness among persons with mental illness, insufficient shelter allowance for people on public income assistance, limited availability of social housing, the ways in which housing benefits limited people's choice of housing and supports, and jurisdictional issues within and across levels of governments.

Within this policy context, key informants described multiple pathways through which citizen-users communicate their experiential knowledge with the expectation of influencing policy decision making. Pathways were explored in two cross-cutting ways: those that involved direct dialogue with decision makers and those that involved indirect communication mediated by others within the policy network. In addition, the pathways were explored as to whether an individual voice (one person's views) or a collective voice (the blended view of multiple people) was being expressed.

Direct Communication

Citizen-user and government informants spoke positively about direct communication. Citizen-users who had the opportunity to speak directly to decision makers indicated that they appreciated the opportunity to engage in this dialogue. These direct conversations could occur informally when a citizen-user happened to be at the same event as a government official but could also be initiated by either the citizen-user or government official. One government key informant noted that "straight from the

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consumer is most valuable" but also acknowledged the limitations in trying to hear the voice of "every individual" with mental health needs.

Despite issues of feasibility, the importance of dialoguing with multiple citizen-users about a policy issue was echoed by many citizen-user, advocate and service provider informants. Hearing multiple ideas from citizen-users reduced the risk of decision makers latching onto policy recommendations that were ill-conceived because they were based on limited knowledge and experience. One advocacy representative noted:

> I've often seen very strange dynamics happen where somebody who … has lived with mental health issues and addictions comes up with a policy recommendation … (and) they have the ear of … (a decision maker) … and it's fraught with issues because this person may not have thought through all of the possible implications ….

To address the challenges of communicating with multiple citizen-users, key informants identified strategies that could provide opportunities for government decision makers to dialogue directly with citizen-users. For example, during the time of the study a group of people that included citizen-users organized a forum to tell their stories and provide policy recommendations to government officials. Both citizen-users and government informants viewed the forum as a powerful means of communication. These perspectives are consistent with a scoping review of public involvement activities done by Mitton and colleagues (2009) in which they found that face-to-face deliberation appeared to result in the perception of having achieved better outcomes.

Social action was also seen by some citizen user, advocate and government key informants as an effective strategy for communicating dissatisfaction with policy. However, one advocacy representative noted that gathering enough people to participate in rallies related to mental health issues could be challenging.

We don't see a lot of fresh new faces of consumers who … begin advocating … maybe people are getting better, maybe people are getting more help or … maybe it's not as polarized as it was in the sixties and seventies and eighties.

Thus, social action was seen as important but was not an activity in which many citizen-users were currently engaged. Others (Barnes, Newman, & Sullivan, 2006) have speculated that governments have increasingly expressed the desire for more citizen participation and emphasized collaborative rather than adversarial decision making. Government commitments to involve citizen-users in this jurisdiction (Manitoba Health, 2003), along with better treatment and services as noted by the informant above, may have created an environment in which social protest was less likely to occur. In addition, organizations that could lead social protest often have mandates that include both service delivery and advocacy. Nelson and colleagues (2008) found that consumer run organizations, especially those with both service delivery and advocacy roles, struggle with whether to work inside or outside the mental health system to advocate for change. This tension may limit both the organization and implementation of social protest activities.

Indirect Pathways

Indirect pathways were ones in which the ideas of citizen-users were translated to decision makers by other policy actors or institutions. Table 1 summarizes the policy actors and institutions that were identified by key informants as having this role and the nature of their mediating role in representing the ideas of citizen users.

The pathways through which the ideas of citizen-user navigated were often complex. Key informants described three themes related to factors that could influence the integrity of the pathways through which the experiential knowledge of citizen-users was gathered and accurately translated to decision makers: the length and complexity of the pathway, the motivations and interests of the translators, and the methods of gathering a collective voice.

Length and Complexity of the Pathway

Key informants spoke about challenges in translating citizen-user voice along channels that included multiple people and layers in organizations. This "trickle-up" approach was particularly salient for service providers. Key informants felt ways in which communication navigated through organizations was impacted by the size, complexity and culture of the organization. Informants believed that smaller organizations could communicate the needs of their clients from a service provision perspective more effectively because the people who communicated with decision makers were more likely to have contact with citizen-users. In large organizations layers of bureaucracy could distort the message. As one government official commented:

If you're told okay you need to start with one level and then it just works its way

up, we know what happens with communication, right. By the time it gets to

where the policy decision maker is it's probably totally different and has a whole

bunch of other people's input on it and tweaking.

Multiple layers could also prevent the message from getting through to decision

makers. One citizen-user described this as information gatekeeping:

If I'm in frontline service and I'm trying to pass on (the message that) these

people need help … you still have to get … through the … gatekeeper. I really

believe there are individuals who decide what kind of information gets through.

These information gatekeepers could function at any level in the organization. The

culture and capacity of an organization could affect whether the negative experiences that

clients had with policy were collected and communicated to decision makers. Thus, the

"trickle-up" occurred through multiple layers of bureaucracy and was filtered by

constraints created by organizational culture. Likewise, one government key informant

noted the importance of government culture in facilitating a balanced approach in which

citizen-user perspectives that were communicated to a government minister also trickled

down to lower levels of internal government decision making.

Perspectives and Interests of the Translators

Key informants acknowledged that the people who assumed mediating roles

within the pathways from citizen-user to decision makers held a variety of perspectives

and interests that could influence how the experiences of citizen-users were

communicated and interpreted. In more formalized arrangements, representatives have

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authority and accountability to those they represent (Pitkin, 1967). Formal representation includes lawyers representing their client in the courts, leaders of advocacy organizations representing their members, and researchers representing the ideas of their participants. However, some roles may not have arrangements for representation and lack authority and accountability to those whose experiences were being translated to decision makers.

Issues of representation and advocacy in translating the experiences and ideas of citizen-users were salient issues for representatives of advocacy organizations and for service providers. Representatives of advocacy organizations saw their role, and were recognized as having a role, in representing the interests and voices of citizen-users. However, conflict could occur if representatives of organizations felt constrained in expressing ideas of citizen-users. One citizen-user cautioned:

> … for the organizations sometimes I bet there's conflict, in a sense of where does your funding come from. Is it coming from the person that you, you really want to advocate against, or for … change? And what sort of relationship do you have with them? That's dangerous ground.

This quote illustrates the balance that advocacy representatives need to maintain in an atmosphere of funding arrangement that could put restrictions on their ability to fully translate the ideas of their citizen-user members. These advocacy representatives may also believe that they need to maintain a middle ground between government and their members in order to maintain relationships and legitimacy with both.

The role of service providers in mediating the pathways of the citizen-user voice was unclear. Service provider informants expressed fairly consistent messages about the

importance of advocating for individual clients but their role in advocating for systems change was more nebulous. One service provider commented:

> We advocate, but we advocate for services. I'm not sure I would think that we'd advocate for the people. I think there's a pretty big difference. I make no particular claim knowing this interest. All I know is that I can accept there are certain things that people need … we advocate for what we believe the need to be, provide that to them. But I think we have to be very careful when we try to say we speak for other people because there are very few agencies that do true advocacy.

Another service provider said that service providers handled issues with larger policy implications "very cautiously". Caution was accompanied by a sense of helplessness in not being able to influence change. Explicit and implicit organizational rules about channels of communication could serve to constrain service providers from communicating the ideas and experiences of citizen-users.

Paradoxically, although some service providers found addressing policy issues difficult, some citizen-user informants believed that service providers were in a unique position to understand and translate the messages about client experiences up bureaucratic channels. One citizen-user was passionate about the potential of this role.

> It's the housing workers; it's the mental health worker, those frontline people that work directly with us. Bringing forth (issues) to their supervisors, their bosses, talking to the organizations and then bringing it the next step.

This suggested an untenable situation. Service providers felt constrained in translating the ideas and experiences of citizen-users through complex channels yet

citizen-users were counting on service providers to translate their experience and influence policy change.

Methods of Gathering the Collective Voice

Key informants emphasized the importance of gathering the collective voice of multiple citizen-users. Although informants valued individual citizen-user stories, policy barriers to individuals can be mitigated with individual solutions that do not change the policy that impacts on others. Public policy is a collective enterprise both in its development and its impacts. Key informants noted the importance of multiple perspectives entering policy discourse.

There are many methods to gather the multiple perspectives of diverse citizen-users. However, informants expressed concern about the skill with which the collective voice is gathered and reported, and the accuracy of the translation of citizen-user ideas to decision makers.

Conclusions, Implications and Future Directions

The results of this study shed light on the multiple ways that citizen-user ideas can enter policy discourses. Direct, individual communication with decision makers can provide a powerful message about policy change. Personal storytelling is relatively accessible to decision makers and may be given more weight by decision makers when other sources of information are inconclusive (Jewell & Bero, 2008). Verbal storytelling can be an important method of communicating experiential knowledge for citizen-users (Restall & Strutt, 2008). There is evidence that theatre (Nisker, Martin, Bluhm & Daar, 2006) and photos (Wang, Morrel-Samuels, Hutchison, Bell & Pestronk, 2004) are other

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ways to tell stories that may promote inclusive policymaking by accepting diverse communication styles.

Beyond individual personal stories, the findings suggest that collective stories are also important within policy decision making. Using collective stories means that efforts are made to understand multiple stories so that commonalities and differences can be identified and appreciated in relation to their intersection with public policies. Qualitative research can contribute to collective understanding of the impact of mental illness on the everyday experiences of recovery (Davidson, Ridgeway, Kidd, Topor, & Borg, 2008). Informants across all four policy actor groups in this study identified participatory action research as a promising practice for the involvement of citizen-users in the collection and dissemination of the experiential knowledge. Research related to the inclusion of citizen-users in policy discourse is a citizenship issue requiring greater support for the funding, production and uptake of research that uses qualitative methods and social action approaches.

Indirect pathways deserve more attention with regard to maintaining the integrity of the pathways. Key informants identified many translators of citizen-user experiences. They identified challenges in maintaining the accuracy of the message from citizen-user to decision maker including changed messages, messages not being transferred, and lack of skills or commitment to gather collective messages. Although the direct involvement of citizen-users and their formal representatives in policy making must be strongly supported, key informants in this study were clear that indirect and informal methods were a reality of policymaking and the integrity of indirect pathways needs to be addressed. The methods of ensuring trustworthiness of communication of experiential

knowledge implemented in qualitative research traditions (Creswell & Miller, 2000) can improve the integrity and perceived legitimacy of the translated voice.

Decision makers must weigh the voice of citizen-users with other sources of information, values and institutional arrangements (Lomas, 2000). Government officials need to develop knowledge, skills and attitudes for facilitating and using experiential knowledge. Policy decisions occur in distinct but not, linear stages: agenda setting, policy formulation, decision making, implementation and evaluation (Howlett, Ramesh & Perl, 2009). Future research should explore how different pathways of experiential knowledge contribute to policy discourse depending on the policy stage. For example, individual story telling may be most helpful at the agenda setting, policy formulation and implementation stages. Forums in which individuals and their representatives of advocacy organizations share a more collective voice of citizen-users' experiences may be most effective at the policy formulation and implementation stages. Systematically collected experiential knowledge through qualitative and mixed methods and participatory action research may be most helpful in the decision making stage.

This research has implications for policy actors. Citizen-users and formal representatives of advocacy groups can continue to use diverse means to share experiential knowledge to inform policy decisions. Individual storytelling, social action, participatory action research and legal means can be used individually or in combination to influence policy. Representatives of advocacy groups can continue to systematically collect the experiential knowledge of their members and promote rigorous and transparent methods to collect and disseminate this information.

The citizen-user informants in this study challenged service providers to examine their role in systematically collecting the experiences of citizen-users to promote policy change. Health professionals have an elite status in policy development yet this study and other literature (e.g., Earnest, Wong, & Federico, 2010; Restall & Ripat, 2008) indicate that they continue to be unclear about their roles in advocating for social change. Citizen-user informants perceived that service providers were in powerful positions to understand how some policies negatively influenced their recovery. Service providers' organizations should examine their practices to determine how they both enhance and limit the translation of citizen-user experiential knowledge.

This research was limited in scope by time, place, policy issue and range of policy actors who gave their input into citizen user involvement. However, the results have illuminated the pathways that citizen-user voices take in informing policy development. If citizen-users are to be included as citizens in a recovery oriented mental health system, action must be taken to enhance the pathways through which their experiential knowledge reaches policymaking processes.

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Table 1						
Mediating Roles						
Families & Informal Supports	Service Providers	Representatives of Advocacy Organizations	Researchers	Media	Courts	Bureaucrats
Communicate citizen-user needs and ways that policy impacts on meeting those needs Communicate own needs and ways that policy impacts on families	Collect individual stories of how policy impacts people's lives Transfer information through the organization to decision makers	Represent interests of members May also have service delivery roles	Systematically collect and disseminate information about citizen-user experience	Collect and disseminate information on citizen-user experience and government policy	Hear and make rulings on challenges to government policy	Passively receive information from other actors to communicate to decision makers Actively solicit information from actors to communicate to decision makers

Chapter 10: Link to Chapter 11

The previous chapter reported findings of this research related to *how* the experiential knowledge of citizen-users enters policy discourse. These findings provide a framework for understanding both direct pathways to policymaking and indirect pathways through which the experiential knowledge is translated by one or more of the diverse policy actors who are also involved in policy discourse. Key informants expressed concerns about the integrity of the indirect pathways suggesting that policy attention needs to be paid to strengthening direct pathways and improving the integrity of indirect pathways.

The next chapter reports on findings related to *what* contextual factors influence the implementation and outcomes of citizen-user involvement. Context, for the purposes of this research, was defined broadly as the factors within social, political and organizational environments influencing citizen-user involvement. This discussion of context is important because it promotes understanding of the factors in the environment that can promote and hinder the pathways, processes and outcomes of citizen-user involvement. Greater understanding of context can provide insight into how environments can be changed to promote involvement.

Chapter 11

Understanding How Context Shapes Citizen-user Involvement in Policymaking

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Introduction

Policymaking occurs within a complex web of inputs and contextual factors. The involvement of citizens in the development of health policy is one input that is gaining attention as governments grapple with increasing their accountability to the public (Government of Canada 1999). Yet the contextual factors that influence citizen input into health policy are under-researched (Abelson and Gauvin 2006). Understanding context is particularly important for involvement of citizens who use mental health and housing services. These citizen-users face multiple barriers to participation in social and political life (Standing Senate Committee on Social Affairs, Science and Technology 2006). The findings reported here were derived from a study that explored the participation of citizen-users in policymaking. These findings focus on the influence of context on involvement. Context was defined broadly as the factors within social, political and organizational environments influencing the implementation and outcomes of involvement.

Theory papers on citizen involvement in policymaking have acknowledged the importance of contextual variables and their influence on process and outcomes (e.g., Chess 2000; Renn et al. 1995). Yet Rowe and Frewer (2004) observed that most evaluation studies seldom do more than mention contextual variables in broad terms. However, there have been three recent research contributions from the United Kingdom (Newman et al. 2004) and Canada (Abelson et al. 2007; Thurston et al. 2005) with direct applicability to health policy.

Newman and colleagues (2004) reported on a synthesis of 17 case studies from forums that engaged citizens in deliberation about policies and services. Using qualitative methodology, they identified several context variables including the broad political landscape, institutional mechanisms and the capacity of the organization to engage in participatory forums. They also noted that the experiences and interpretations of participants including previous experience with social action, the meanings that participants placed on participation and their symbolic constructions of the forum also were important. Symbolic constructions of participants by officials also emerged as a contextual factor.

In a Canadian study, Thurston et al. (2005) reported on five case studies in the Calgary Health Region. Using a grounded theory approach they developed a conceptual framework that situated public participation within the context of health policy. They identified five major contextual elements: the participation process, policymaking in the region (i.e., how "space" was made for the initiative to influence policy), the social context including political and symbolic institutions, the policy community and the health of the population.

Abelson et al. (2007) used a conceptual map to inform the investigation of the role of context variables on a deliberative mechanism delivered in five Canadian provinces. The map included: a) political contexts related to relationships and trust, b) community related to the characteristics of the population, c) research-decision maker relationships, d) organization context related to the commitment of organization staff to the initiative, and e) decision making considered the kind of issues being considered and the time frame for decisions (p. 2119). Using a quasi-experimental comparative design

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they reported several findings related to context including that methods and their application had to be appropriate to the context, and that organizational leadership and commitment were important.

These studies described a broad range of contextual factors that influence citizen involvement from personal and interpersonal factors to those related to institutional and socio-political environments. The study reported here builds on existing research by exploring how context influences the involvement of citizens who have faced multiple structural barriers to social and political life. The aim was to highlight important contextual variables that could facilitate implementation and outcomes of involvement. As governments grapple with meeting expectations of citizens and including their voices in policymaking, greater understanding of how context influences involvement can identify ways to involve those citizens who may face some of the greatest barriers to inclusion in policymaking.

Design

The study used qualitative instrumental case study methodology (Stake, 2005) focused on citizen-user involvement in the policy field of mental health and social housing in Manitoba from September to December 2008. The study was approved by the University of Manitoba Health Research Ethics Board.

Data Collection

Data collection included key informant interviews and documentation review. Twenty-one (21) key informants were purposively selected from four groups of policy actors: representatives from advocacy organizations (n=5), citizen-users (n=6),

government officials (bureaucrats and elected) (n=4), and service providers (n=6). The groups were not mutually exclusive because some informants reported belonging to more than one group. Five (5) informants were between the ages of 21 and 35 years, 6 were between the ages of 36 and 50 and the remaining 10 were between the ages of 51 and 65. Thirteen (13) informants were women. The majority of informants were interviewed using a semi-structured interview guide subsequent to giving informed written consent. In one case an unstructured interview was used because the informant had a unique perspective. Narratives about informants' own experiences with policymaking were elicited as well as their ideas and perspectives on the larger field of citizen-user involvement in mental health and social housing policy. Specific questions and probes explored contextual factors that influence citizen-user involvement and policy decisions.

Documents included government policies on consumer participation, initiatives and reports related to mental health and social housing, and reports from contemporary forums. The researcher also maintained reflective field notes after every interview and during data analysis which served to create an audit trail detailing the researcher's decision making throughout the research process.

<div align="center">**Data Analysis**</div>

Interviews were audio-recorded and transcribed verbatim. NVivo (Version 8) software was used to manage and code transcripts and documents, write memos and explore data through queries and modeling. An inductive qualitative paradigm modeled after methods described by Miles and Huberman (1994) guided data analysis. An initial coding scheme was developed based on the key topics of the interview guide. Descriptive

and pattern codes and sub-codes were added into the coding scheme as they emerged through line-by-line review of the transcripts. After analysis of 19 transcripts the coding scheme was revised by reviewing each code and sub-code looking for redundancies and inconsistencies. The final two interviews were coded using the revised coding scheme. No new codes were identified during the analysis of these final interviews suggesting theoretical saturation of the data based on the sample.

Findings

Five themes emerged from the data related to the contextual influences on the processes and outcomes of citizen-user involvement in policymaking. These influences are depicted in Figure 1.

Socio-political Environment

Key informants in all four groups identified the socio-political environment as important to the implementation and outcomes of involvement. Informants emphasized the negative impact of socially constructed views of people with mental illness. These attitudes could extend from paternalistic views of "people with mental health problems should be spoken for", not taking citizen-users' input seriously, and preconceived notions about how people with mental health and housing needs will behave. Some citizen-users told stories of how these negative constructions influenced their personal experiences with mental health and housing as well their involvement in policymaking. In addition, poverty, substance use and race could add multiple layers of sigma, prejudice and discrimination.

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Participants also viewed society's perceptions of the policy issue as limiting the possibility that citizen-user input would lead to positive change. One citizen-user talked about the social-political notion of the deserving and undeserving poor as a substantive barrier to policy change:

> well it's stigma … I really feel this country needs to get over, this province, this country, needs to get over the notion that there is deserving poor and undeserving poor.

This informant went on to talk about how some members of the public believe that "there are people who are just lazy and … are taking money away from the people who really need it." These perceptions of public attitudes related to "deservedness" are consistent with other research (Knightbridge et al. 2006). Negative public attitudes could impact on the political will of decision makers to address the needs and solutions proposed by citizen-users resulting in structural discrimination so that mental health related programs and services do not receive the share of the public funding consistent with the burden of illness (Kirby and Keon 2004).

Institutional Characteristics

Key informants identified two themes related to the characteristics of institutions that influenced whether citizen-users' voices would influence policy decisions. These characteristics were commitment and capacity.

Commitment referred to the organization's dedication to including citizen-users in policymaking. Key informants talked about transparency of decision making as a facilitator of effective involvement and noted the importance of organizations and the

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people within them having strong values related to citizen-user involvement. Values needed to be translated into behaviours that made it possible to implement citizen-user involvement throughout the organization. In response to questions about how information from citizen-users traveled up and down organizational hierarchies, one government official commented:

> … if (the department) were to move to a more consumer-centred model and if the minister were to decide that was going to be the case, well that'd be nice but it would take, I don't know what it would take to really change my day-to-day activities unless that was also like coming at every level of the organization saying … here's how we're operationalizing it.

The importance of organizational commitment was reiterated by a leader in a not-for-profit service delivery organization. She talked about her organization's approach to including the voice of service recipients in organizational decisions by ensuring "the community is well reflected on the staff and on the board." Key informants also talked about the importance of commitments to "to work in partnership" with the community and willingness to change.

Capacity referred to the availability of resources needed to engage citizen-users in policymaking. Representatives of advocacy organizations recognized their role in influencing social policy but felt constrained by limited resources to build a collective voice and to promote the development of citizen-users as advocates.

For government, capacity included the availability of funding to make policy changes recommended by citizen-users. Even if they valued consultation with citizen-

users, the consultation became meaningless if there was insufficient funding to make policy changes.

Participant Characteristics

Key informants noted that personal characteristics, related to knowledge, skills, and attitudes, could impact positively on inclusion of citizen-users in policy decisions. These characteristics are summarized in Table 1.

In addition to knowledge, skills and attitudes, life experiences of mental illness and social housing were viewed by key informants as providing a positive perspective that both citizen-users and decision makers could bring to policy discourses. In the case of decision makers, several informants perceived that decision makers who had personal experiences with the impact of mental illness were more sympathetic to issues confronting people with mental health and housing needs. These experiences were viewed as influencing decision makers' willingness to include citizen-user voices in policy development and could trump political philosophy in strengthening resolve to implement policy changes supportive to people with mental health and housing needs.

In the case of people with mental illness, life experiences seemed to have a paradoxical effect. On the one hand their experiential knowledge was viewed as valuable. On the other hand their experiences with mental illness and poverty could impact negatively on their ability to become involved in policy development. Several informants thought that the impairments and cyclical nature of many illnesses could make it difficult to sustain important relationships and to participate in forums designed for the healthy.

Key informants noted that trying to meet basic needs could create additional barriers to involvement. As one advocacy representative stated:

> … if you're a person with mental health issues trying to scrape by every day worrying about your housing and what you're going to eat and all of those things, how can you be thinking about public policy when really what you're thinking about is what are you going to eat tonight.

The urgency of meeting basic needs could supersede addressing broader political concerns even when public policy directly influenced the ability to meet basic needs.

Opportunities for Involvement

Key informants noted that having opportunities to become involved in policymaking was an important contextual factor. Building relationships was viewed as one potential means to facilitate ready access to decision makers.

Some citizen-user key informants noted the importance of providing a variety of options for "speaking out" about their experience to assist them to develop confidence. One service provider noted how her agency strongly encouraged program participants to attend all gatherings such as general meetings to facilitate their involvement "so that they can see that their voice does and can make a difference." Several citizen-users emphasized the importance of creating opportunities for positive experiences. As one noted:

I think that the system has to be more accommodating … (so) that people aren't

scared to stand up and say 'this is wrong' and not be made to look ridiculous if

they happen to disagree with stuff.

This quote not only suggests the importance of diverse opportunities but that these

opportunities occur in an environment of trust and respect. Opportunities for involvement

need to accommodate to the ways in which citizen-users can express their ideas, opinions

and disagreements.

Other Influences on Policymaking

A fifth theme from our key informants was the influences on policy making by

factors internal and external to government policymaking processes. Internal influences

included competing priorities for policy attention, the philosophies and values of the

governing party, cabinet member and bureaucrat opinion, and availability of finances.

Government criteria for deciding to implement a policy change also influenced which

decisions were made. For example, one government official noted the importance of

criteria about whether the suggested policy change would be practical, whether it would

meet a need and whether it would provide value for money.

External factors consisted of legal and constitutional obligations as identified in

Human Rights Legislation and the Charter of Rights and Freedoms, and other sources of

information such as experiences of other governments, research evidence, other policy

actors and the public. Incentives were also important catalysts. During the time of the

study, the Mental Health Commission of Canada (MHCC) was convening a research

demonstration project to initiate new approaches to housing in the city of Winnipeg. The

Request for Proposals (MHCC, 2008) explicitly stated that advisory committees will be created and that "consumer involvement is mandatory on Advisory Committees". The Commission was exerting influence through this funded project to promote the uptake of "best practice" housing models and the role of citizen-users in an advisory capacity. Although the role of citizen-users was not well defined and was constrained by the parameters of the project, this initiative demonstrated how an external factor could promote a culture of inclusion of citizen-user voices.

Discussion

The findings of this study identified contextual factors important to citizen-user influence on policy. Although depicted as isolated factors, they are conceptualized a complex web of interrelated factors that influence each other and policy making. At least two characteristics of this web of contextual factors are worthy of further discussion because they are salient to the population and policy issue addressed in this case study and contribute to earlier work on the contextual influences of citizen involvement in health policy.

First, we highlight the importance of the socio-political environment's direct influence on policy decisions as well as its indirect influence on other contextual factors. The importance of the social-political landscape has been identified by others (e.g., Abelson et al. 2007; Newman et al. 2004; Thurston et al. 2005). Thurston et al. (2005) noted how symbolic institutions such as race, gender and religion could impact on citizen involvement and we emphasize the importance of social constructions of illness and poverty. Our key informants gave testimony to the ways that negative constructions of

mental illness could impact on whether citizen-users were seen as able and valuable contributors to policy debates and whether policy ideas that affect them were seen by decision makers as important issues to address. Not only could the socio-political environment impact directly on power within policy making processes but could have more circuitous and pervasive influences through other factors. For example, negative constructions of people with mental illness could influence the culture of institutions which, in turn, could limit opportunities for people to become involved in policymaking.

The findings suggest that, although other aspects of the socio-political landscape such as the communications of governing parties (Newman et al. 2004) may be important, the social constructions of people with mental health and housing needs may overshadow other aspects. The negative constructions of people with mental illness are well documented (Kirby and Keon 2004) and appear to be exacerbated by poverty (Wilton 2004). Ongoing research needs to examine the influence of these constructions on involvement. Initiatives by the Mental Health Commission of Canada (n.d.) related to its anti-stigma campaigns and local initiatives to work with mass media to reduce the negative portrayals of people with mental illness (e.g., Mental Health Literacy Network 2009) need to be evaluated for their impact on policymaking.

Second, we highlight institutional responsibility for creating structures that engage citizen-users. Key informants in our study identified multiple obstacles to citizen-users' involvement in policymaking including the nature of mental illness and the burden of poverty. Citizen-users have supported the concept of personally building their skill and knowledge to enable involvement (e.g., McDaid 2009). However, responsibility for inclusion should rest more heavily on the institutions that create structural barriers to

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involvement. Requiring citizen-users to fit into existing managerial structures creates the potential for co-option of an elite category of citizen-user and advocate (Rutter et al. 2004) who will engage in traditional governance models of consultation and decision making (Newman et al. 2004). While this approach may have a place in policy debates, sole reliance on this method of involvement does not achieve the goal of inclusiveness inherent in citizen engagement.

Alternatively, social theories of disability suggest that society's failure to take into account the needs of people with impairments in its organization and structures creates disabling conditions (e.g., Oliver 1990). Examining ways that involvement mechanisms are constructed may reveal how they exclude many people with mental health and housing needs. Demands for specific forms of rational communication and discouragement of more emotive forms (Church 1996) are examples of how citizen-users can be excluded from policy debates, their contributions minimized or discounted and existing power structures maintained or reinforced.

Limitations

This case study was bounded by geographic location and time limiting the scope of the exploration of citizen-user involvement in policymaking. This limitation was partially overcome by the review of documents that provided historical context for the policy issue and the ability of key informants to speak about their past and present experiences. Nonetheless, policymaking is a long and complex process (Howlett et al. 2009) for which this case study only provided a small snapshot in time and place. In addition, the sampling frame did not include all of the potential policy actor groups that

contribute to discourse this policy field. Future research could explore perspectives of members of the discourse community who are more distal to policymaking, e.g., federal government officials, professional organizations and the media.

Conclusions and Policy Implications

Space must be made for diverse types of involvement that are in keeping with the lifestyles and communicative preferences of citizen-users. The responsibility for the development of these opportunities relies on the re-creation of standards and norms for involvement mechanisms that are co-created with people with mental health and housing needs. Consumer run advocacy organizations have a role to play in systems change (Janzen et al. 2007) and in supporting the co-creation of accessible involvement mechanisms. They also have a role in facilitating citizen-users' participation in these mechanisms through individual skill building and the establishment of social networks which Barnes, Newman and Sullivan (2006) argue are important to people's motivations to become involved. However, the development of these mechanisms relies most heavily on government institutions to develop capacity and decision makers' knowledge, skills and attitudes - as described in Table 1 - to create accessible structures. For example, involvement mechanisms can use diverse modes of communication including those that are visual, creative and emotive such as those that have been demonstrated in "Other Voices" forums sponsored by the Canadian Council on Learning (2007), theatre (Nisker et al. 2006) and photovoice (Wang et al. 2004). Engaging citizen-users in policymaking requires more attention by policymakers to the creation of environments that support diversity.

Identifying contextual factors that influence citizen-user involvement creates awareness of how changing context could influence citizen-user involvement in policymaking. Many citizen-users experience socially constructed barriers to participation in social and political life. This research has suggested ways of reducing barriers to involvement in policymaking by addressing the negative social constructions of people with mental health and housing needs, developing institutional and personal commitment and capacity for involvement, and co-creating diverse opportunities for citizen-users to engage in policy discourse. Future research should continue to examine the influence of changes in contextual factors on the quantity, quality and outcomes of citizen-user involvement in policy decisions.

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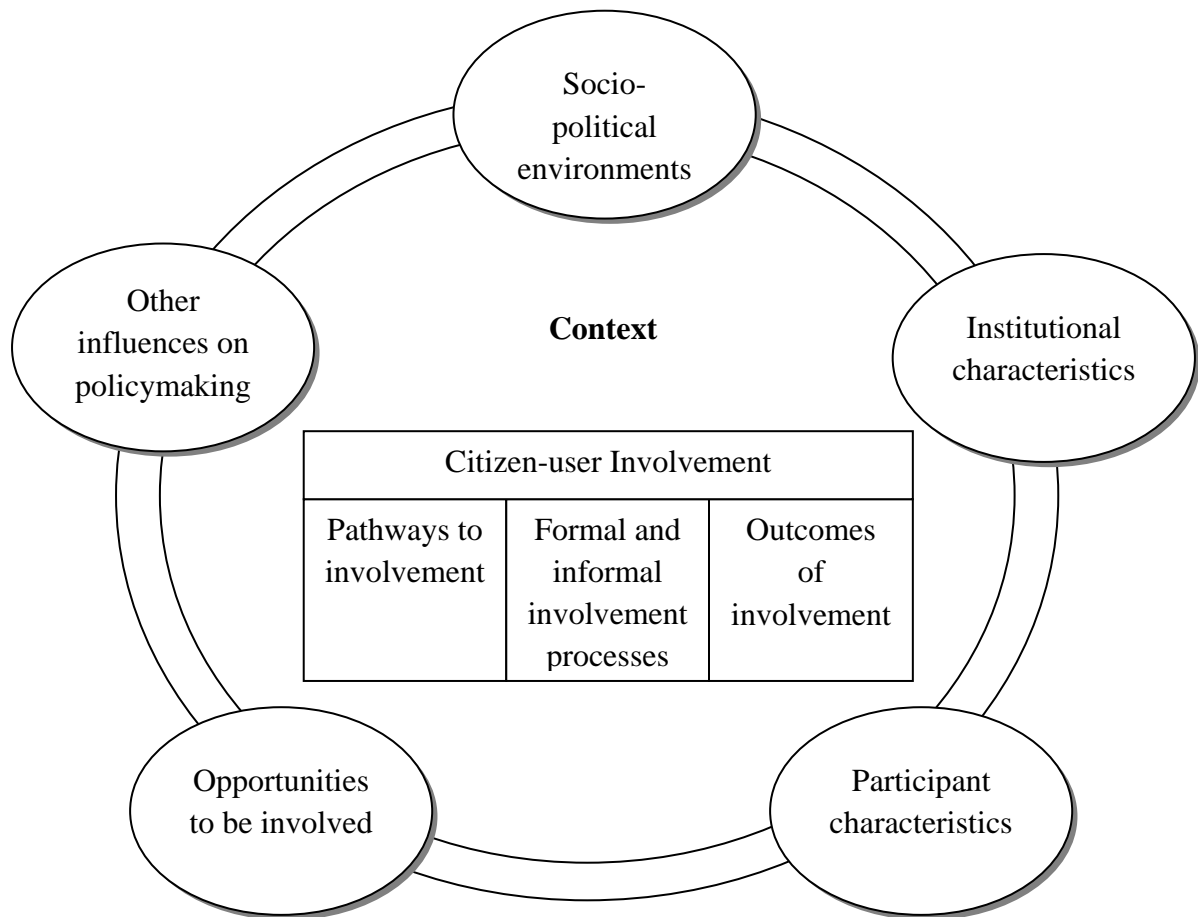Figure 1. Contextual influences on citizen-user involvement in policymaking

Socio-political environments

Other influences on policymaking

Context

Institutional characteristics

Citizen-user Involvement		
Pathways to involvement	Formal and informal involvement processes	Outcomes of involvement

Opportunities to be involved

Participant characteristics

Table 1		
Knowledge, Skills and Attitudes Impacting Positively on Citizen-user Involvement		
Knowledge of:	Skills to:	Attitudes:
• the policy issue • political systems including timing, strategy, and who has power and influence.	• express ideas, experiences and positions • collect and express accurate information to support one's position • listen and understand others' ideas, experiences and positions • elicit information and apply it to the policy issue in an accurate and meaningful way	• persistence • resiliency • openness to learning • the will for involvement to happen • optimism about making a difference • positive representations of people with mental illness

Chapter 12: Researcher Reflections and Study Limitations

An important element of qualitative research is to understand the positioning of the researcher and the process of the research. Researchers can reflect on how they have impacted on the research and how the research has impacted on them. Documentation of these reflections can serve to bring transparency to the processes by which the researcher designed and conducted the research and to their conclusions and recommendations. These reflections can also assist to illuminate the limitations of the study.

Researcher Reflections

As a registered occupational therapist I had the opportunity and privilege to meet many people with severe and persistent mental illness who often had social housing needs. One of the strong underpinnings of the practice of occupational therapy is client-centred practice (Townsend et al., 2007). This philosophical framework resonated with my own belief that, to facilitate engagement in occupations, the client's needs, goals and values were paramount. However, I came to struggle with two tensions related to my role as an occupational therapist and as a manager in institutional and community based mental health services systems.

First, it became exceedingly evident that many of the efforts made by clients to become engaged in society were undermined by larger public policy and social factors. This extended from the organization of the health system to the lack of living, working and leisure environments that were sufficiently inclusive to accommodate their needs and goals. As an occupational therapist trained in the 1970s, the focus of intervention in medicine and other health disciplines was to address individual factors, a focus that

persists today. Thus, I felt unequipped to address the larger social and political factors that created such substantial barriers to participation in society.

The second tension was created by the growing uptake of ideas in the 1990s about clients having a say in their individual care – a hallmark of client-centred practice – and health services. Despite the rhetoric, the development, implementation and evaluation of services remained closed to most clients. I observed and participated in efforts to demonstrate an interest in client involvement such as finding a "good" client to sit on a quality committee or the administration of satisfaction surveys when patients were discharged from hospital. None of these attempts appeared to approximate the meaningful involvement of clients in service development.

Perhaps the most influential event that shaped my desire to research citizen-user involvement in health policy was my membership on a provincial government sponsored mental health advisory committee as a professional representative from 1998 to 2001. The committee was very large, presumably to include all stakeholders, both professional and consumer. I ended my tenure on the committee with the belief that there had to be better ways to meaningfully engage citizen-users.

In 2003, I began an academic appointment at the University of Manitoba. I subsequently began to research citizen-user involvement by gaining the perspectives of citizen-users about participation in health service planning and evaluation (Restall & Strutt, 2008).

Thus, I arrived at the beginning of the current research with:

- Education and clinical practice in occupational therapy

- Experience in working in the fields of child and adult mental health services

- Professional connections with people in the policy network of mental health services

- An academic appointment and previous research in citizen-user involvement

- A belief that it is the right of people to participate in decisions that affect their lives and that current methods of involving citizen-users are often inadequate and at times, destructive

My experience and stance within the research project had several potential impacts. First, my relationships within the mental health policy network facilitated the recruitment of an advisory committee and potential participants. My previous experience as an occupational therapist and manager working in mental health and experience on the provincial advisory committee provided a somewhat emic perspective that facilitated awareness of the actors, language, points of contention and processes of the policy field of mental health. However, at the initiation of the study I was not immersed as an actor in the policy field of mental health and housing and had little direct experience in social housing. Therefore, I also had an etic perspective that made me continuously aware of the need to challenge my assumptions and preconceived notions of the policy field. This was perhaps most evident in relation to understanding perspectives on homelessness.

My belief that mechanisms to involve citizen-users in policy decisions have been inadequate may have influenced my line of questioning during key informant interviews. Although I made efforts to develop my interview guide in a manner that did not

emphasize this perspective, I may have been more willing to pursue participant discourse related to the barriers to involvement than to pursue testimony about positive experiences. I was aware of this potential bias during the study but perhaps more so during analysis than data collection. Additional interview questions that specifically sought positive experiences may have served to ensure a balanced approach.

In conducting this research I have become even more committed to the ideals of citizen-user involvement. Through this, and a previous study (Restall & Strutt, 2008), I have had the privilege of talking to dozens of citizen-users about their involvement in decisions about policy and services. The question is not can they be involved; the answer to that is a resounding "yes". The question is whether social and political institutions are willing to create structures that make it possible for their voices to be heard. As a researcher with the means to communicate and advocate for change I have grown more aware of the importance of using that power to transfer it to those whose very survival depends on better mental health and housing policy.

Through this research I have also become more acutely aware of the challenges of conducting research in a policy area such as this one. Several of the limitations of the present study are discussed next.

Study Limitations

This research was limited in several ways. As an instrumental case study, it was bounded by geographic location and time. This bounding of the case served to provide definition but also limited the scope of the exploration of citizen-user involvement in policymaking. This limitation was partially overcome by the review of documents that

provided historical context for the policy issue and the ability of the key informants to speak about their past and present experiences and knowledge of citizen-user involvement. Nonetheless, policymaking is a long and complex process (Howlett, Ramesh, & Perl, 2009) for which this case study only provided a small snapshot in time and place.

To enhance understanding of involvement processes it would have been beneficial to have had access to a specific forum in which citizen-users were actively involved in policymaking. The work of the Cross Department Coordination Initiative (CDCI) of the Manitoba Government could have provided such an opportunity. Although approached about the potential to access a forum or involvement process, the CDCI indicated that it did not have a suitable initiative during the time of the study. This lack of access meant that potential documents internal to government or specific mechanisms could not be accessed. In addition, the ability to do ethnographic observations of mechanisms and to conduct interviews focused on specific involvement mechanisms limited the range of data that could be collected. Future research could include ethnographic observations. However, such access is anticipated to be difficult due to the apparent reluctance of governments to hold their citizen involvement activities up for analytical scrutiny. Examples of willingness for such evaluation appear to be very rare (Abelson & Gauvin, 2006). This unwillingness to allow research access to involvement activities restricts the generation of knowledge that can contribute to improvements in the outcomes of involvement including better policy.

On the other hand, addressing the larger policy field of mental health and housing built on previous research that has focused more often on discrete involvement

mechanisms. What was lost in specificity was gained in an understanding of the broad perspective of the pathways through which citizen-users access or attempt to access policymaking.

A third limitation of this study was the purposive sampling of key informants. The strategy that was used in this study was to choose four policy actor groups from which to recruit policy actors. Citizen-users and government officials were chosen because of their close proximity to the issue of citizen-user involvement in public policymaking. The other two groups, representatives of advocacy organizations and service providers, were chosen because they have been included in what Howlett et al. (2009) call the *discourse community*. Groups more distal to policymaking but are still part of the discourse community were not sampled. These groups included federal government officials, members of the media, and representatives from professional organizations. Future research could explore perspectives of members of these policy actor groups.

Qualitative researchers often suggest that sampling should continue until data is saturated theoretically (Morse, 1995). In this study, the sample size was determined by the number of policy actor groups as well as through the emergence of new themes during data analysis. No new themes emerged from the data during the analysis of the last two key informant interviews suggesting saturation of the data. In addition, the member checking process did not reveal any additional information or ideas that the key informants wished to add. However, it is difficult to know whether the data were, in fact, saturated. It is possible that a more diverse sample may have added new insights, codes and themes. For example, the sample was confined to people living in an urban area and

it is difficult to know whether data collected from people in rural or northern areas of Manitoba would have generated additional themes.

The member checking process consisted of developing a plain language summary of the findings and giving participants the opportunity to provide feedback or add information. This process left the initiative for contact with participants. One individual could not be contacted. Of the 20 participants who were sent the report, 2 responded. One respondent made a general comment about ensuring that the final report had specific recommendations and the other indicated agreement with the report. Participants who did not respond may have not have had anything else to add; however, this can not be confirmed.

This research was focused on the involvement of people who use mental health and housing services in the development of health and social policy. More participatory approaches to the research may have added more insights. Although a Community Advisory Group provided advice on research questions and interpretations of results, they were not intimately involved in the design of the study or the collection and analysis of data. The goal of participatory action research is to enact social change (Kemmis & McTaggart, 2005). Investigating and facilitating change in how citizen-users are involved in policymaking is an area for which participatory action research may be ideally suited.

As a PhD thesis this research was, at many points in time, a solo effort particularly related to the analysis and interpretation of the data. I was the only person who read all the transcripts in their entirety and developed the initial coding scheme. Acknowledging the limitations in my own interpretations of data, I also acknowledge the

ready availability and value of mentorship from my advisor. In addition, the

multidisciplinary makeup of my Thesis Committee and Community Advisory Group was

helpful in providing checks and balances to my interpretations. The member checking

process also assisted to provide some evidence of trustworthiness that my results were

reflective of the opinions and perspectives of the key informants.

Despite these limitations this research builds on existing research by increasing

understanding of citizen-user involvement in policymaking. The conclusions and

recommendation discussed in the next chapter are intended to promote more effective

involvement and provide structure for the evaluation of formal involvement mechanisms.

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Conclusions

The aim of this research was to develop a model for the implementation and evaluation of citizen-user involvement in health policymaking. The model is depicted below. The purpose of the model is to guide the development of activities that can promote the implementation and measure the outcomes of citizen-user involvement.

Figure 1. Model of Implementation and Evaluation of Citizen-user Involvement in Health Policymaking

In the centre of the model is a triangle that represents formal and informal citizen involvement activities. The triangle emanated from previous research (Appendix D) (Restall & Strutt, 2008) that sought the perspectives of people who use mental health services about how they would like to be involved in health service and policy development. These involvement processes are the points at which citizen-users engage with decision makers and other policy actors in policy discourse. The previous research identified important characteristics of these processes, notably that they be flexible, inclusive and respectful. The data included in the current study built on this previous research and extended the model by exploring the potential outcomes of involvement, the pathways through which citizen-users access policy discourses, and the contextual factors that influence citizen-user involvement.

The model also depicts the outcomes of citizen user involvement. The current research identified four categories of outcomes: substantive, instrumental, normative and personal. Benefits and risks of involvement were identified within each category. Substantive outcomes relate to the achievement of the goal of the policy and improved health and well-being for the population of people with mental health and social housing needs. Normative outcomes relate to increased social and political participation of individual citizen-users and the population. Instrumental outcomes relate to transparency of decision making processes and better relationship between policy actors and government. Personal outcomes relate to empowerment of citizen-users and the management of personal risks. Identifying these categories as outcomes can guide the implementation and evaluation of involvement processes as well as suggest ways to manage the inherent risks for individuals and institutions.

To the left of the model are two types of pathways through which the voices of citizen-users gain access to policy making: direct and indirect. Direct pathways are those through which individual and collective voices of citizen-users dialogue directly with decision makers. Indirect pathways represent the ways in which the voices of citizen-users are mediated by other policy actors. Although participants in this research acknowledged that indirect pathways were a reality of public policy decision making, they expressed concern about the integrity of the pathways. Understanding the strengths and limitations of the pathways through which citizen-users' voices enter policy discourses can guide action to strengthen their integrity.

The involvement processes, pathways and outcomes are situated within the contextual environment of policymaking. Participants in the current study identified five contextual factors that influence citizen-user involvement and decision making related to policies impacting citizen-users. These factors were: the socio-political environments, institutional characteristics, participant characteristics, opportunities to be involved and other influences on policymaking. Of these factors, two were particularly salient for this population and policy issue. The first was the socio-political environment that included negative social constructions of people with mental health and housing needs. The second factor was the institutional characteristics that can support or impede access of citizen-users to policymaking and the uptake of their ideas into policy decisions.

Recommendations

The model developed from this research has several potential applications. The value of such a model is to increase understanding of the pathways through which

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citizen-user voices enter policy discourses and how their engagement can be influenced

by the nature of the pathways and contextual factors of policymaking. The model also

assists those interested in engaging citizen-users to understand the potential outcomes of

these processes and better manage the risks and enhance the benefits. Greater

understanding of pathways, processes, outcomes and contexts leads to recommendations

for action. The following section summarizes recommendations for action. I will begin

with overall recommendations and then address recommendations for each policy actor

group and their organizations. I will conclude with directions for future research.

Overall Recommendations for Action

1. *Address the negative social understandings of people with mental health and housing*

   needs through anti-stigma campaigns and by highlighting positive examples of

   citizen-user engagement in policy development

   Negative attitudes toward people with mental health issues and behaviours

associated with these attitudes were variously described by participants in this study as

stigma, prejudice and discrimination. These attitudes and behaviours contributed to the

exclusion of citizen-users from social and political life. Link and Phelan (2001)

conceptualized stigma as occurring when "elements of labeling, stereotyping, separation,

status loss, and discrimination occur together in a power situation that allows them" (p.

377). These theorists emphasized the importance of the power relationships between the

group doing the stigmatizing and the stigmatized group. These power relations and the

attitudes and behaviors associated with stigma create social conditions in which people

who are stigmatized have fewer opportunities in society. Key informants in the current

study viewed this social exclusion as limiting opportunities for citizen-users to be included in policy discourse and the implementation of policy decisions supportive of this group.

Link and Phelan (2001) noted that discrimination could occur in the form of individual discrimination or structural discrimination. Individual discrimination occurs when an individual labels a person in a certain way that causes him or her to discriminate against that individual. For example, a landlord may refuse to rent a suite to someone he or she knows to have mental illness because of his or her preconceived ideas about how that person may behave. The second way that discrimination may impact a person in a stigmatized group is through structural discrimination in which institutional practices disadvantage the stigmatized group. For example, the practice of institutionalization may have contributed to stigma by decreasing contact between people with mental illness and the rest of the public (Mulvale, Abelson, & Goering, 2007). In addition, media institutions such as newspapers can create structural discrimination by depicting people with mental illness in a manner that is stigmatizing (Corrigan et al., 2005).

Action is needed to address stigma and resulting attitudes and individual and structural discrimination. Strategies to address stigma has focused on three areas: protest, education and contact (Rusch, Angermeyer, & Corrigan, 2005). Protest is often directed against public discourse about mental illness that could be considered stigmatizing. For example, protest can take the form of a letter writing campaign to a media outlet objecting to the way that people with mental illness have been represented in a news story. Although such protest can be effective in decreasing the number of stereotyping

statements made about people with mental illness, little is known about its effect on attitudes (Rusch et al., 2005).

Education as a strategy to reduce stigma has had variable results and success in improving attitudes toward people with mental illness. Relative success may be related to the type of education, the target audience and the messenger. In their review of studies related to educating the public about mental disorders as an illness caused by biogenetic factors, Read, Haslam, Sayce, and Davies (2006) concluded that people's beliefs about the biogenetic causation of mental disorders were related to more negative attitudes and behaviours. This suggests that promoting ideas about mental disorders as a biological abnormality may increase rather than decrease public stigma, prejudice and discrimination. However, the New Zealand Government's "Like Minds, Like Mine" project has included active involvement of people with mental illness in a national media campaign and has shown promising trends in promoting more positive public attitudes toward people living with mental illness (Vaughan & Hansen, 2004).

Contact between a stigmatized group and a group who stigmatizes them has been one of the most researched strategies for reducing stigma. Positive findings have been demonstrated with people with mental illness (e.g., Link & Cullen, 1986) and those who are homeless (Lee, Farrell, & Link, 2004). Interestingly, Lee et al. found, in their cross sectional survey, that various types of contact including face to face as well as learning about homelessness through others (e.g., the media) had a positive influence on people's attitudes toward the homeless population. Paradoxically, there was a small group for whom intense exposure to people who were homeless had the opposite, more negative effect.

Given the potential for both contact and education to positively affect people's attitudes toward citizen-users, a combined strategy may have the most impact (Rusch et al., 2005) particularly with the active involvement of citizen-users in the planning and development of the strategy. To specifically address the engagement of citizen-users in policymaking these strategies could include communication of examples of how citizen-user can contribute positively to these processes. For example, a Winnipeg Free Press editorial (2010) described efforts to redevelop core area housing to help people with mental illness and addictions who are homeless, part of a federal-provincial housing project. The article identified how people who were clients of a local shelter were interviewed to ensure the design met their needs. Such stories can highlight, to the general population, the potential for citizen-users to be involved in policy initiatives at various levels.

It is also incumbent on individual policy actors to explore their own socially constructed ideas about citizen-users and how their attitudes and behaviours can support or impede citizen-user involvement. Positive perceptions of citizen-users as people who have the right to engage in policy discourses can create a context in which involvement is more likely to occur. In turn, citizen-user involvement can result in normative outcomes in the form of increased participation of citizen-users in social and political life. Most importantly, however, is the need to address the behaviors and structures that exclude people with mental illness from achieving citizenship rights and from engaging in the "practice" of citizenship.

2. *Embrace a socio-political model of disability to advance a recovery oriented mental health system by using a policy lens that targets the social and political barriers to*

health and well-being and promotes recovery and quality of life for people with

mental health and social housing needs.

For decades, disability advocates have been fighting for recognition of a social-political model of disability that acknowledges the role of social environments in creating barriers to engagement in social life and the inclusion of the experiential knowledge of citizen-users in policymaking (Chamberlin, 1990; Jongbleod & Crichton, 1990a). Despite the shift from an individual to a social model of understanding disability, public policy (Jongbleod & Crichton 1990a; Prince, 2004) and service delivery (Jongbleod & Crichton, 1990b) in Canada have been slow to catch up. For citizen-users, the achievement of a recovery oriented mental health system (Standing Senate Committee on Social Affairs, Science and Technology, 2006) depends on the recognition of the ways that policy can support or impede their citizenship rights. It also depends on their opportunities to contribute their experiential knowledge, ideas and resources to improving policy that eliminate barriers. All policy actors need to recognize the importance of a model of disability that promotes social inclusion. Policy options and decisions need to be viewed and evaluated with a lens that advances recovery by addressing the social and political barriers to health and well-being and to inclusion of people with mental health and housing needs in policymaking. Approaching policymaking from a value base of social inclusion can strengthen the potential for citizen-users to have a meaningful voice in policies that affect them.

Such a lens can assist to identify and diminish the structural discrimination that limits opportunities for people to engage in policymaking. For example, involvement mechanisms that rely solely on verbal discourse during group meetings can be

discriminatory to those for whom verbal discourse, long attention spans and group

interaction is very difficult. Thus, policymaking needs to be viewed from a lens of

inclusiveness to address the structural practices that keep people from participating. The

United Nations (2006) Convention on the Rights of People with Disabilities, to which

Canada is a signatory, affirms the right of people to "participate in public and political

life" (Article 29). More attention needs to be paid to determining how laws, policies and

practices enhance or inhibit human rights of people with mental health problems. More

action is needed to reform discriminatory laws, policies and practices and those that

inhibit participation (Burns, 2009).

Recommendations for Policy Actor Groups

Service providers

1. Recognize their mediating role as translators of experiential knowledge
through bureaucratic channels.

Not all service provider informants in this study perceived that they had a role in

communicating the experiences of their clients and patients up bureaucratic channels.

This seemed to be most true for individuals at the front lines of larger organizations.

However, many citizen-user key informants believed that front line service providers

were in a unique position to understand their experience and had access to channels

through which that experience could be communicated to decision makers. Service

providers and the organizations in which they work need to articulate their role in

communicating citizen-users' experiences with policy. This in no way suggests that

service providers should *speak for* citizen-users. Instead, they need to develop the skills

to be accurate translators of citizen-users experiential knowledge. Service providers need to systematically collect experiential knowledge to create better understanding about how policy impacts both individuals and groups. This action will need a shift in focus from the more tradition medical model of individual care and understanding of disability to a social model that considers the impact of social policy on creating barriers to social participation (Oliver, 1990). This action will also require careful scrutiny of service providers' professional interests and the ways they use their elite status to influence policy.

2. <u>Shorten and strengthen the channels from client voice to decision maker</u>.

Key informants in this study were very concerned about the integrity of indirect pathways from citizen-users to decision makers. Service provider organizations have a responsibility to shorten and strengthen the pathways by increasing the opportunities for citizen-users to dialogue directly with decision makers in forums that ensure the integrity and transparency of the dialogue. In addition, service provider organizations can evaluate their ability to systematically collect and communicate the experiences of their clients with health and social policy. For example, organizations can develop processes for front line workers to document the number of people on their caseloads who are living in inadequate housing, the policy barriers for finding safe and affordable housing for each of these people and potential solutions to the policy problem. Service providers need assurances that such documents are valued and will contribute to policy discourse.

Representatives of advocacy organizations

1. <u>Systematically collect members' ideas and experiences</u>.

Advocacy organizations, particularly those that have consumer boards, have an important role to play in addressing policy issues. They can provide valuable links to citizen-users. These organizations should be diligent in the ways they include citizen-users and systematically collect and document their ideas and experiences. In this way they can strengthen the integrity of their roles in translating the experiential knowledge of their citizen-user members.

2. <u>Facilitate the creation and utilization of multiple opportunities for citizen-user involvement in policy discourse</u>.

Advocacy organizations should continue to develop methods to include citizen-user in policy discourse. They can be good role models as they engage citizen-users in their own organizations. They can also develop new mechanisms that are in keeping with diverse preferences and communicative style. Their roles can include:

a) Providing peer support for citizen-users who engage in policy forums

b) Providing opportunities for citizen-users to gain skills and experience in communicating in committees and public forums. One example is the Canadian Mental Health Association - Manitoba Division's (n.d.) Partnership for Consumer Empowerment

c) Sponsoring, encouraging, and supporting linkages that will develop participatory action research projects targeted at policy issues

d) Monitoring research related to policy issues and work with researchers and others to develop methods to communicate this knowledge to their members

e) Working with government officials to develop flexible, inclusive and respectful involvement mechanisms

f) Seeking opportunities for citizen-users to engage in policy debates in diverse ways and at various stages of the policy cycle

Government officials

1. <u>Build internal culture and capacity for citizen-user involvement</u>.

This research has suggested that commitment of governments to include citizen-users in policy discourse is an important source of support to such involvement. This commitment can be expressed in many ways but includes expectations that citizen-users must be involved. This expectation must go beyond documented commitments such as the Manitoba Government's policy, *Consumer Participation in Mental Health Service Planning, Implementation and Evaluation* (Manitoba Health, 2003). The commitment must extend to its officials developing the knowledge, skills and attitudes to effectively engage citizen-users. Officials must apply the time and effort required to ensure that citizen-users' voices are heard and contribute to policymaking processes.

In addition, commitment to citizen-user involvement must permeate throughout policymaking processes. For example, the best involvement strategies implemented by those mandated with developing policies can be overruled or discounted by more senior decision makers. A culture and capacity for valuing citizen-user involvement must weave throughout the policymaking cycle from agenda setting to policy formulation, decision making, implementation and evaluation.

Health policymaking is a highly political process impacted by multiple contextual factors. Government officials who are developing and making policy decisions need to be

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aware of the influence of context on involvement processes and the inclusion of citizen-

users' ideas in decisions. Addressing these contextual factors can be an important means

of advancing citizen-user involvement.

2. <u>Facilitate the development of new ways to engage citizen-users</u>.

The traditional mechanisms of committees and public forums need to be

augmented by more creative methods of engagement that take into account citizen-users'

diverse communicative preferences and styles. For example, theatre (Nisker, Martin,

Bluhm & Daar, 2006) and photovoice (Wang, Morrel-Samuels, Hutchison, Bell &

Pestronk, 2004) have been used as mechanisms for people to communicate with decision

makers about issues of importance.

3. <u>Develop expertise that will assist decision makers to use citizen-users'</u>

<u>experiential knowledge to inform policy</u>.

Policymaking is influenced by multiple sources of interests and ideas (Howlett,

Ramesh & Perl, 2009). Governments need to develop processes to use experiential

knowledge as it is weighed in the context of other sources of information such as

quantitative research evidence, professional interests and public opinion. The use of

citizen-users' experiential knowledge should be considered in the context of the stage of

the policy cycle and whether the knowledge is gathered and communicated directly or

indirectly, formally or informally, and whether the voice of citizen-users is blended with

other policy actors. For example, the formally constituted Provincial Advisory

Committee on Mental Health Housing and Related Support Services (2008) provided

policy recommendations to the government within the policy formulation stage of policy

making. The voice of the one citizen-user on the committee was blended with the voices

of other policy actors also part of the committee. In contrast, an individual may meet informally with a government minister to recommend a specific policy option. Alternatively, a decision maker may read the results of a qualitative participatory action research project that gathered the experiences and recommendations of a group of citizen-users. There needs to be space for individual story telling as well as more systematically collected experiential knowledge in the form of rigorous qualitative research at various stages at the policy cycle. However, the source, method and intent must be clearly understood and the information weighed accordingly.

4. <u>Facilitate the integrity of the pathways from citizen-users to decision makers by demanding systematic and rigorous methods of gathering experiential knowledge</u>.

This can be accomplished through the use of both quantitative and, particularly, qualitative research methods.

5. <u>Engage in evaluations of the outcomes of citizen-user involvement in policymaking</u>.

Formal involvement mechanisms convened by governments to engage citizen-users need to be evaluated relative to their normative, substantive, instrumental and personal outcomes. Only through rigorous evaluation of all factors can there be shared learning that can be used to improve processes and outcomes. These evaluations need to be participatory to mirror the values of citizen engagement.

Future Research

The findings from this study suggest several key directions for future research. Methods for conducting evaluations of citizen-user involvement need to be developed and enhanced. Greater empirical understanding of the process of involvement and the

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contribution of context will contribute to this emerging body of knowledge. Potential

research questions include:

- *How can substantive, normative, instrumental and personal outcomes be measured?*
  Development of tools and methods for measuring outcomes that can be applied across
  involvement activities can promote more systematic evaluation of citizen-user
  involvement and facilitate comparison and learning across contexts. These
  evaluations need to be conducted within a framework of citizen-users' right to self-
  determination (Charlton, 1998) with citizen-users as full participants in the
  development, implementation, analysis and interpretation of outcomes. These
  approaches are consistent with traditions of participatory action research.

- *How does citizen-user involvement evolve over time?* This study examined
  involvement in a small window of time but policymaking is a long process. Future
  research can engage in a longer term examination and observation of involvement
  over various stages in the policy cycle and includes types of involvement and levels
  of decision making influence.

- *What are the relative impacts of formal versus informal involvement processes?* For
  example, do formally constituted committees that include citizen-users have more or
  less influence on policy decision making than informal indirect meetings between a
  citizen-user and government official?

- *How do changes in context influence the quantity, quality and outcomes of citizen-
  user involvement?* This research and other studies (Abelson, Forest, Eyles, Casebeer,
  Martin, & Mackean, 2007; Newman, Barnes, Sullivan & Knops, 2004; Thurston et
  al., 2005) suggest that context has a profound effect on involvement. Future research

could examine how changes in specific contextual factors, such as organizational

capacity, impact on the processes and outcomes of citizen-user involvement.

- *What is the relative contribution of various types of citizen-user involvement (i.e.,
  individual, collective, direct and indirect) at different stages of the policy cycle?* For
  example, direct individual stories and indirect collective voices may be most
  informative at agenda setting stage, whereas rigorously collected qualitative research
  and evaluation on citizen-users' collective experiences of the impacts of policy
  alternatives may be most informative at the decision making stage. The following
  table proposes ways of considering the contribution of experiential knowledge at
  various stages of the cycle.

Table 1: Contributions of Citizen-user Experiential Knowledge within the Policy Cycle

Policy Stage	Contribution of Citizen-user Experiential Knowledge
Agenda Setting	- Individual stories - Collection of individual experiences - Representation of multiple interests (e.g., illness, culture, socio-economic status) - Public discourse
Policy Formulation	Individual and collective ideas gathered through consultations, committees, forums and research.
Decision Making	Systematically gathered, collective information (e.g., qualitative research and program evaluation) about the impacts of policy alternatives on citizen-users
Policy Implementation	- Individual and collective ideas gathered through consultations, committees and forums - Representation of multiple interests (e.g., illness, culture, socio-economic status)
Policy Evaluation	- Representation of multiple interests to generate evaluation questions - Systematically collected evaluation about the impacts of the policy decisions - Individual stories about the impact of the policy decisions

Sylvestre and colleagues (2007) have observed that most research related to housing for people with complex mental health needs has addressed therapeutic values focused on improving the well being of individuals. However, they noted that little research has addressed values related to citizenship. Research related to the inclusion of citizen-users in policy discourse is a citizenship issue and may require a shift in approaches from traditional health research models. This shift may require increased capacity for social justice oriented action research through ongoing development of training programs for researchers (Nelson, Poland, Murray, & Maticka-Tyndale, 2004) and increased support for action research in health related funding agencies (Walsh, Grant, & Coleman, 2008).

Conclusions

This research has added to knowledge about the important components of citizen-user involvement in health policymaking. Policy decisions about mental health service delivery have traditionally been made within a closed subsystem. However, governments have increasingly appeared to be willing to include citizen-users, family members and voluntary organizations in the policy discourse (Kirby & Keon, 2004). The inclusion of more actors in policymaking can shift power and increase transparency of decision making processes. Thus, it has value for governments in legitimizing its decisions. This research has suggested that, if governments are truly committed to including citizen-users in policymaking, they need to enhance the integrity of pathway through which citizen-users' experiential knowledge enters policy discourse and address the contextual factors that can limit involvement. They also need to pay attention to the outcomes of involvement. Inclusion in social and political life is a right of citizenship. People with

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mental health and social housing needs have important experiential and other knowledge

and skills to contribute to policymaking. The challenge is the ongoing search for the

means to ensure that their voices are heard and carry weight in policy decisions.

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Appendix A

Involvement Process Criteria

Type of Process	Process Criteria	Relevant Evaluation Questions	Indicators
Goal Definition	• Goals are defined and agreed to by all involved.	How do citizen-users, decision makers, and others involved in the involvement process define the goals of involvement? How similar are the goals defined by citizen-users, decision-makers and others?	• Organizational documents state the goals of involvement. • Citizen-users, decision makers and others state that they know the goals of the process. • Citizen-users, decision makers and others state that they agree with the goals
Levels of Participation	• The expected level of participation (i.e., communication,	What level of participation is expected by health planners and citizen-users?	• Organizational documents state the level of participation expected of health planners, citizen-users and

	consultation, participation) matches the level of participation possible using the specific involvement mechanism.	Is the involvement mechanism used appropriate to the level of participation expected?	others. • Organizational documents describe the involvement mechanisms that are used. • The involvement mechanism provides the level of involvement expected.
Representation	• There is early involvement of citizen-users in the policy discourse. • The full range of citizen-user interests, opinions and perspectives related to the policy issue have been	At what stages in the policy process does citizen-user involvement occur? How have participants been selected? What efforts have been made to engage people who are most	• Documents state that citizen-users are included in all stages of the policy debate: agenda setting, formulation, decision making, implementation and evaluation. • Documents record the demographic characteristics of the population

	represented in the policy discourse.	marginalized in the policy debate?	impacted by planning decisions. • Documents record the interests, opinions and perspectives related to the policy discourse. • Stakeholders state that the full range of citizen-user interests, opinions and perspectives related to the policy issue have been represented in the policy discourse.
Opportunities for Discourse	• Participants have the opportunity to present ideas, debate the ideas of others and make decisions. • Rules of discourse during	What is the nature of the discourse during citizen-user involvement? How is the agenda decided? How are the rules of discourse decided?	• Organizational documents and stakeholders state that discourse includes opportunities to present ideas, debate the ideas of others and make decisions.

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	involvement are negotiated and agreed to. • Multiple and diverse opportunities are available for citizen-users to participate.	How does the discourse include or exclude citizen-users presenting their ideas, debating their ideas and making decisions? What amount and type of opportunities are available for citizen-user participation?	• Organizational documents state the ways that agendas and rules of discourse • Stakeholders state that they have negotiated and agreed to the rules of discourse. • Stakeholders state that citizen-users have multiple opportunities to present and debate ideas and make decisions.
Access to Information	• Citizen-users are given information to allow them to participate in the policy discourse.	What information are citizen-users given? How is the information given? How is the transfer of information	• Citizen-users are satisfied with the amount, type and relevancy of information provided. • Mechanisms are in place for

	• Information provided to citizen-users takes into account the message, the target audience, the messenger, and the ways that the message is transferred. • The methods by which information is provided are evaluated.	evaluated? How relevant to citizen-users is the information? What is the level of satisfaction of citizen-users with the amount and type of information provided?	evaluating the transfer of information.
Resources and Supports Available	• Involvement mechanisms are funded. • Involvement mechanisms have reasonable time and	How are involvement mechanisms funded and to what extent? What are the time and cost requirements for officials and	• There is a budget for citizen-user involvement. • The cost (financial and opportunity) are tracked.

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	cost demands on officials and citizen-users. • Citizen-users have access to resources and supports to facilitate their participation.	citizen-users? What are the opportunity costs of involvement mechanisms for officials and citizen-users? What are the resources and supports available to citizen-users? Are the funding, resources and supports sufficient?	• Citizen-users are satisfied with the resources and supports available to them to participate in involvement mechanisms. • Citizen-users and officials perceive funding, resources and supports as sufficient.

Appendix B

Involvement Outcome Criteria

Type of Outcome	Outcome Criteria	Relevant Evaluation Questions	Indicators
Social Benefits			
Instrumental	- More perceived legitimacy for public policy decisions - More citizen-user confidence in policy decisions - Increased trust in public institutions - Increased accountability of public institutions for policy	Are the policy decisions that were made perceived by citizen-users as valid? Is there increased trust in the RHA, and provincial government by citizen users? Do government institutions provide information to the public about how and why policy decisions were made?	- Citizen-users state that they perceive policy decisions are legitimate. - Citizen-users state that they have more trust in the RHA and provincial government after their involvement. - Government communication to the public describes how and why

		Do citizen-users and service	policy decisions were made.
	• Better relationships among policy actors, especially between citizen-users and service providers • Better relationships within communities • Increased social and community capacity to address issues of concern	providers perceive that their relationships have improved? Are there more networks within the community that are working on health and social issues?	• Stakeholders state that their relationships have improved after involvement. • Coalitions and networks have developed around health and social issues.
Substantive	• Higher quality programs and services • Improved population health status	Has social housing improved for people who use mental health services? Has the overall health and well-	• There is an increase in the amount and type of social housing for people who use mental health services.

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		being of the population needing mental health and housing services improved? Have resources been allocated to support mental health housing initiatives?	• Self reported health and wellbeing has increased for people who need mental health and social housing. • There are designated funds to address mental health housing initiatives.
	• Better or efficient use of resources		
Normative	• Increased participation of citizen-users in public policy decisions that affect them • Shifts in power relationships from the more to the least powerful	How many citizen-users participated? Did citizen-user involvement influence policy decisions? Do policy actors perceive that there are shifts in relative power between professionals and health planners to citizen-users?	• The number of citizen users who are involved in public policy decisions increases over time. • Policy actors perceive that there are shifts in power between professionals and health planners to citizen-users.

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Individual Benefits			
Citizen-users	• Increased feelings of empowerment • Increased knowledge about health and social service supports, services and policies • Feelings of satisfaction about working with others	What were the positive outcomes of participation to citizen-users? How satisfied were citizen-users with the process?	• Citizen users report increase feelings of empowerment. • Citizen-users report increase knowledge about health and social service supports, services and policies. • Citizen-users report increased feelings of satisfaction about working with others in health policy planning.
Officials	• Increased capacity of officials to engage citizen-users	What did officials learn about engaging citizen-users? What did officials learn about the	• Officials report increased knowledge and skills to engage citizen-users.

		perspectives of citizen-users?	• Officials report increased knowledge about the perspectives of citizen-users in policy.
	• Increased knowledge about the perspectives of citizen-users in policy		
Negative and Unanticipated Outcomes			
Other outcomes	• To society • To individuals • To organizations	What were the negative or unanticipated outcomes of participation?	• Negative outcomes were identified, analyzed and addressed.

Appendix C

Involvement Context Criteria

Context Variable	Context Criteria	Relevant Evaluation Questions
Political Landscape	• Discourses of the governing parties • The nature of the policy subsystem including power relationships • The level of relationships and trust within the policy subsystem • Symbolic institutions such as race, gender and religion that influence power and decision-making	What are the discourses of the governing parties related to citizen-involvement? Who is part of the policy subsystem? What are the discourses within the policy subsystem? What are the power relationships within the policy subsystem? What influences do symbolic institutions have on power relationships in the policy subsystem? If there is more than one subsystem, how do the subsystems relate or overlap?

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Site of citizen-user involvement	• The site at which involvement occurred, e.g., level of government, RHA, local community	Who or what entity requested or convened citizen-user involvement activities? How close is the entity to the decision-making body? How formalized are the mechanisms for influence and decision making?
History of citizen-user involvement in the jurisdiction	• Prior experiences in the jurisdiction • Mandates for citizen-user participation (formal or informal) • Perceived credibility of citizen-user participation	What other citizen-user involvement activities have occurred? What are the expectations for citizen-user involvement? What are the opinions of citizen-users and officials about prior involvement activities?
Institutional factors	• Commitment of the organization to citizen-user involvement	What is the overall capacity of the institution to initiate citizen-user involvement? What is the commitment of the institution to the

	• Willingness of the organization to rebalance power outside professionals and managers • Ways that issues are identified and addressed within the organization	process and outcomes of citizen-user involvement? What is the usual method of identifying and resolving issues within the organization(s)?
Participant factors	• Prior experience of all participants (citizen-users and officials) with social action • Meanings that participants attributed to citizen-user involvement • Symbolic constructions of citizen-users by officials	Who is participating in the citizen-user involvement forums? What are participants' past experiences with social action? What meanings to participants ascribe to citizen-user involvement? What symbolic constructions do officials have of citizen-users? What symbolic constructions do citizen-users have of officials?

| Characteristics of the policy issue | • Whether decisions about the policy issue are expected to change governance or operational structures • Whether decisions are targeting formal or informal policies • Timeframe for policy decisions • Level of research evidence about the policy issue • Types and sources of knowledge related to the policy issue | What type of change is expected to occur in the organization as a result of the citizen-user involvement initiative? What is the timeframe for decisions that are expected to be impacted by citizen-user involvement? What is the current knowledge base about the policy issue and the policy options? |

Appendix D

Participation in Planning and Evaluating Mental Health Services: Building

Capacity

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BRIEF REPORT

Participation in Planning and Evaluating Mental Health Services: Building Capacity

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The participation of people who use mental health services in service planning and evaluation has become increasingly important in recent years. Health planners and people who use services are seeking information about how to enable participation that is meaningful and impacts positively on service delivery. This qualitative study explored the perspectives of people who use mental health services on participation in mental health service planning and evaluation. Sixty-three people from diverse backgrounds participated in either a focus group or interview. Themes were extracted from the data and resulted in a conceptual framework that can be used to guide the development and evaluation of participation.

Keywords: policy, participation, planning, evaluation

The involvement of people who use mental health services in the planning and evaluation of service systems has become increasingly important for health planners. Involvement may result in services that are more acceptable and accessible (Crawford et al., 2002) and of higher quality (Linhorst & Eckert, 2002). This study explored the perspectives of people who use mental health services about their involvement in planning and evaluating service systems.

The rights of people to participate have roots in the concept of empowerment. Empowerment is a paradigm that guides the provision of support to persons with mental health issues and emphasizes health, abilities, personal control, effecting change, and resources (Chamberlin, & Schene, 1997; Clark & Krupa, 2002). At a service systems level, the empowerment paradigm considers how the service system exerts power over people who use the services (Clark & Krupa, 2002). Power imbalances may be reduced when people who use services participate in service system planning and evaluation (Ochocka, Janzen, & Nelson, 2002). Despite a small but growing body of literature on the benefits, supports and barriers to participation, there is little empirical evidence about effective mechanisms of engagement and the long-term outcomes to the quality of the services as a result of

these initiatives (Crawford et al., 2002; Simpson & House, 2002).

One of the challenges in systematically evaluating the effectiveness of participation processes may be related to an issue described by other authors (Clark & Krupa, 2002; Selzer, 1997) as a lack of shared understanding of what participation means. The development of a conceptual framework for participation is an important step in promoting greater understanding and can be used to establish indicators for effective participation that can be empirically tested. Such a framework can assist health planners to become more accountable for participation processes based on principles that emphasize the rights of people who use mental health services to contribute to public policy decisions.

The purpose of this study was to build on previous research on participation. We sought the perspectives of people who use mental health services on participation and the ways that health planners can facilitate involvement of people in meaningful and effective participation in health service and policy development. Previous studies in this area have had small sample sizes or have focused on the perspectives and experiences of people with prior involvement in participatory processes or both. Our study sought diversity in perspectives. We included people with and without mental health service planning and evaluation experiences. We also sought perspectives from people with varied backgrounds living in urban, rural or more remote communities. Diverse perspectives were essential to the creation of a framework that can be used to develop and empirically evaluate participation and hold health planners accountable for effective participation processes.

Method

Design

This research consisted of a qualitative design using focus groups and individual interviews. A combination of focus groups and interviews was used for two reasons. First, we wanted to respect people's preferences for participation and to include people who may not have participated if offered only one method of participation. Choice was possible in all but the most remote locations in which focus groups were not feasible. Second, through the use of two methods of data collection we obtained two sources of narrative, the single voice of individual interviews and the blended voices of focus groups. These different sources of narrative allowed us to increase the trustworthiness of our results through the triangulation of data sources (Patton, 2002).

Participants

We recruited participants from diverse geographic and socio-cultural environments in Manitoba, Canada through a flier distributed by service providers and consumer groups. Thirty-seven people participated in focus groups and 26 people participated in individual interviews. The sample consisted of 46 women and 17 men with an average age of 48 years (range = 26 to 66 years). Forty-six (73%) participants reported that they were currently using mental health services and 48 (76%) reported that they had used services for more than 3 years. The sample was diverse in terms of educational level with 35% being a university or college graduate, 33% being a high school graduate and the remainder having not completed a high school education. The majority of participants (59%) reported a family income of less than CA$15,000.

Procedures

The University of Manitoba Health Research Ethics Board approved the study. All participants provided written informed consent. The semi-structured interview guide was pilot tested with two people who met the inclusion criteria for the study. Focus groups lasted approximately 2 hours. Between 3 and 8 participants attended each group. Individual interviews were 1 hour or less in duration.
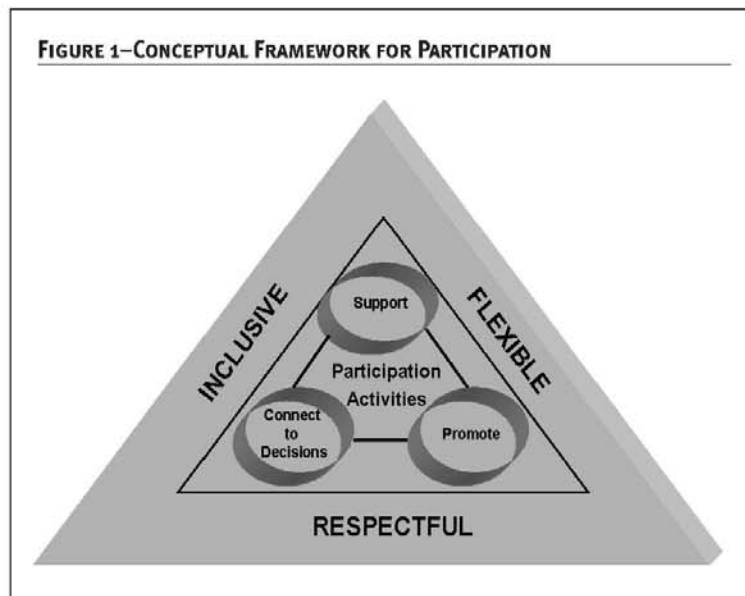
Data Analysis

Focus groups and interviews were audio-taped and transcribed verbatim. NVivo qualitative software (QSR, 2002) was used for data management. Analysis was done by developing a coding scheme based on the initial interview guide, then introducing codes and sub-codes as themes emerged through line-by-line review of the transcripts. Memo writing during the analysis served to elaborate assumptions and identify comparisons and patterns in the data (Charmaz, 2000). The first author coded all transcripts. The second author reviewed initial transcripts and results to increase trustworthiness of emerging themes. An interim summary (Miles & Huberman, 1994) from an initial analysis of the data was sent to the first 30 participants who were invited to send written comments or attend a workshop. Five people sent written comments and 12 people attended the workshop.

Results

Figure 1 depicts a conceptual framework that evolved from the data analysis. It identifies factors that participants believed enable participation activities.

Enabling Participation

The development of respectful, inclusive and flexible processes was a strong theme. Table 1 summarizes par-

FIGURE 1–CONCEPTUAL FRAMEWORK FOR PARTICIPATION

veys, writing, storytelling and public speaking. Regardless of the activity, participants wanted their investment of time and energy to have tangible outcomes. Participants needed assurances that the results of participation processes would be used to make positive changes rather than to legitimize decisions that had already been made by organizations. Most participants wanted to participate so they could improve the lives of people with mental illnesses. As one participant noted, "I would be willing to knock my head against the wall over and over again hoping that I could contribute in some fashion and be heard and help."

Participants also had various opinions about the level of decision making they wanted. Some participants were comfortable having real influence about changes to the service system while others wanted to participate by having their stories heard and taken into account when decisions are made.

ticipants' perspectives on the factors that contribute to these processes. Participants also shared ideas about the actions that health planners need to take to facilitate participation in service planning and evaluation (Table 2).

Participation Activities

Participants had many opinions about the types of participation activities that should be available to people. They suggested committees, interviews, varied employment opportunities, sur-

Discussion

The results of this study suggest that, from the perspective of users of service, definitions of participation should only include those activities for which there is a direct connection between the activity and the service system decisions. Models of participation in mental health service development have included information exchange as a basic level of participation (Hickey & Kipping, 1998; Peck, Gulliver, & Towel, 2002). For participants in this study, participation activities which consisted solely of information exchange were, at best, a waste of time and, at worst, exploitation. People did not want to participate for the sake of legitimizing what health planners had already decided, but rather to make a real impact on decisions that improve services.

TABLE 1–RESPECTFUL, INCLUSIVE AND FLEXIBLE PARTICIPATION PROCESSES

- Opinions are valued
- All participants are open to change
- Contributions are recognized
- Participation processes are transparent
- Action occurs that has a positive impact on the health system
- Skills of individuals are utilized
- Plain language is used
- Confidentiality is maintained
- There is effective leadership
- A team approach is used in which there are common goals, interpersonal relationships and clear mechanisms for conflict resolution and decision making.
- People with a variety of experiences and at differing stages of recovery are included
- Populations that are impacted by decisions are invited to participate
- Processes are free from prejudice and discrimination
- Meetings are scheduled taking into account participant's schedules and safety
- Meetings are conducted in ways that are comfortable for the participants

TABLE 2—FACILITATING PARTICIPATION IN SERVICE PLANNING AND EVALUATION

Support	Promote	Connect Participation to Decisions
• Offer tangible support such as food, transportation, financial compensation	• Develop multiple and varied opportunities for involvement	• Communicate how participation activities influence service planning, delivery and evaluation
• Provide encouragement and guidance	• Inform people about opportunities for participation through word of mouth, public service announcements and posters in community locations	• Communicate how participation activities influence policy formulation and evaluation
• Provide the information needed to fully participate		
• Develop opportunities for peer support		
• Develop resources and supports to enable advocacy and self-advocacy		

The results of this study indicate that many different kinds of participation activities must be available to people. To be inclusive, exceptional efforts must be made to reach out to people who would not normally participate (Higgins, 1999). Participation activities must actively engage people who face barriers because of severity of illness, social isolation, language proficiency, geographic isolation, cultural and ethnic diversity and poverty. Creative ways of engaging people are needed. In our study, storytelling became an important component of contributing to knowledge. Health planners must provide multiple ways to have stories heard and to use the information from these stories to improve services (Krogh, 1998, Pivik, 2004).

Many of the underlying principles identified by participants in this study are consistent with previous literature in the area (e.g., Clark & Krupa, 2002; Crawford et al., 2003; Lammers & Happell, 2003; Lord & Church, 1998; Nelson, Prilleltensky, & MacGillivary, 2001; Ochocka et al., 2002). The use of plain language, valuing diverse opinions, building interpersonal relationships, flexibility in processes, offering tangible and other supports and sharing resources have all been identified as important ways to equalize power differentials between people who use services and service providers. Power differentials and prejudice arising from race were also important to some participants in our study. Respectfully working with differences resulting from ability, race, class and gender is a critical component of participatory activities (Krogh, 1998; Lord & Church, 1998).

Conclusions

Previous research has made important contributions to understanding the perspectives of people using mental health services on participation. Much of this research has had small sample sizes or has focused on participation in service delivery, consumer-run businesses and research from the perspectives of people who have been involved in these activities. Our recruitment strategy sought diversity in geographic locations and backgrounds and included many people who had never been in-

volved in participation activities. People who use mental health services continue to face power differentials in many areas of community life and have limited opportunities to participate in service system planning. Democratic values assert that citizens have a right to participate in public policy decisions that affect their lives (Abelson et al., 2003). Clark and Krupa (2002) argue for more concerted efforts to focus on the rights of people who use mental health services as citizens. Finding mechanisms to provide opportunities for people to assert their rights regardless of skills, interests, levels of recovery and geographic location is an important goal for health planners. The conceptual framework presented here was developed from diverse perspectives of people who use services. It has application as a means to facilitate understanding about participation between people who use mental health services and health system planners. This framework can guide the creation and evaluation of opportunities and environments that promote, support, and respect people's rights to participate.

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Appendix E

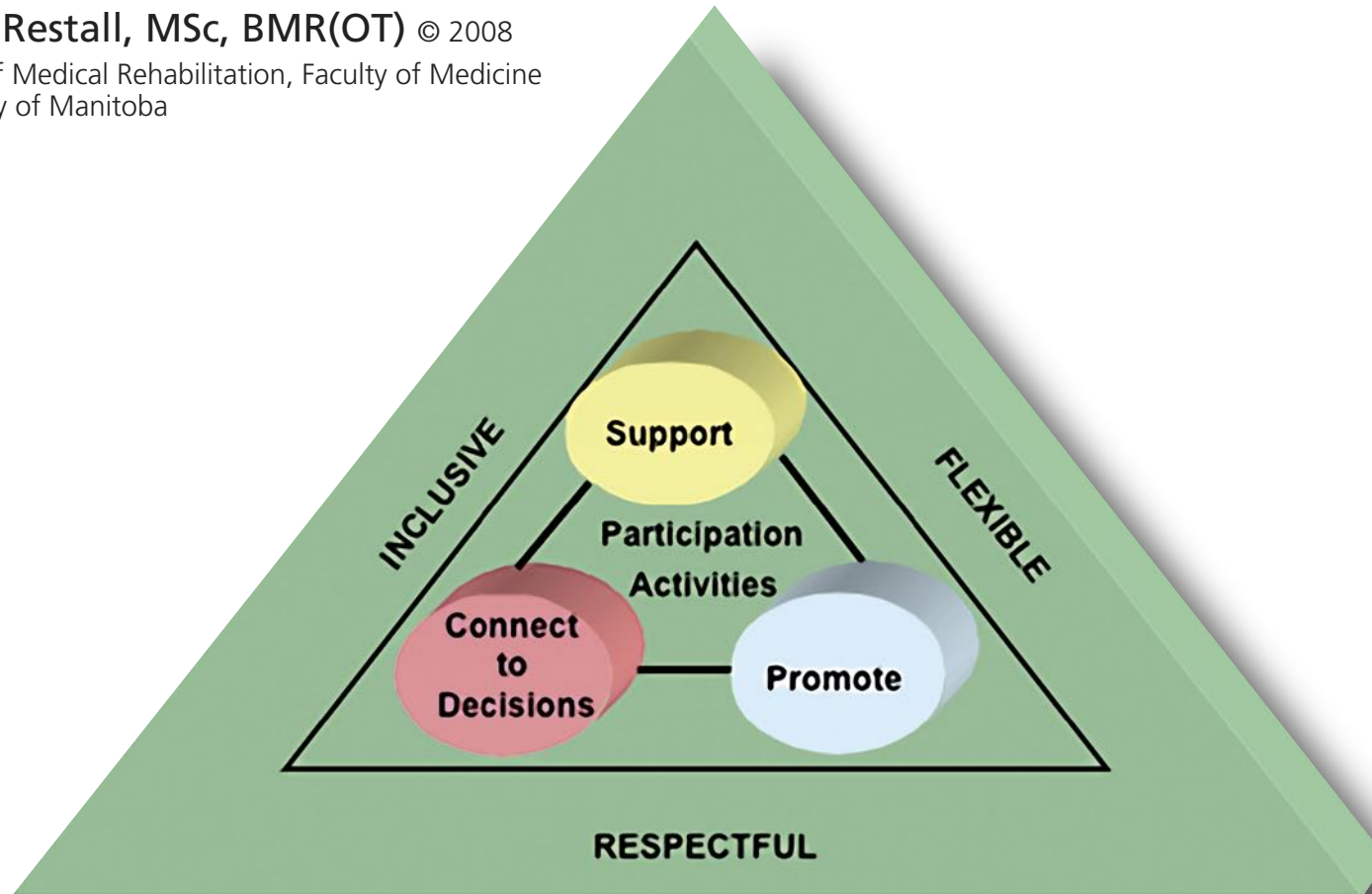**Tool for Implementation and Evaluation of Citizen-user Involvement**

Tool for Implementation and Evaluation of Citizen-user Involvement

Gayle Restall, MSc, BMR(OT) © 2008
School of Medical Rehabilitation, Faculty of Medicine
University of Manitoba

Acknowledgements

Introduction to the Tool

People who need and use mental health services (citizen-users) have the right to take part in decisions about how services are provided. The Tool for Implementation and Evaluation of Citizen-user Involvement will help mental health organizations to involve people who use services participate in service planning.

We made the tool after interviewing 63 people who used mental health services. [1] They helped us define what it means to participate. They also described what organizations need to do to make it possible for people to participate. We also looked at articles that talked about how people can participate in planning health services. The tool is the result of this work.

How the Tool Can Help

This tool can be used by organizations such as hospitals, health authorities, and community programs. Many things affect decisions about the way the mental system works and how services are provided. The goal of the tool is to help organizations to include people in these decisions in two ways. First, the tool can measure how well they are including people in decisions about services. It also can show them how to improve how they involve people. The tool can be used to improve decisions about a large program, a small service or a health policy. The tool provides a way to encourage more involvement of people who use mental health services in service planning. It tells organizations what has to happen for people to participate. It gives organizations a way to assess how well they are including people in making decisions about services.

[1] Restall, G., & Strutt, C. (2008). *Participation in planning and evaluating mental health services: Building capacity. Psychiatric Rehabilitation Journal*, *31*, 334-338.

Using the Tool

The tool describes what should be done to involve citizen-users and what to assess to find out if organizations are including citizen-users in planning services. It provides a guide to how participation could be assessed. Organizations can think about their own environments and use the tool as a guide to assessing their organization.

The tool has 5 columns. The first three columns show what to look for when assessing if an organization includes people in decisions about services. The last two columns show how to find out if an organization includes people in decisions about services.

The first column includes the **dimensions** of participation. These are factors that all organizations need to have for people to participate in decisions about services. The next column is called **criteria**. It tells us what organizations need to do in each of the dimensions. Organizations can see how well they are meeting each of the criteria. The third column is called **indicators**. Indicators tell us how well organizations meet the criteria. Indicators help us decide the types of questions to ask when evaluating experience and documents. For example, do people say that the criteria are being met? Do written documents state that the criteria are being met? This column gives specific examples of what to look for in people's responses and in documents to show that the criteria are being met.

The last two columns show how to evaluate if people are participating. The first way to see if people are participating is by talking to people. This is called **evaluation of experience**. The second way is through **evaluation of documents**. Both ways of evaluating are important. They tell us how the organization is achieving the criteria defined for good participation practices.

Steps for Using the Tool

The following are the steps to follow to use the tool.

Step 1   Look at each dimension (column 1) to see how it fits your organization. Think about how each criterion (column 2) fits within its dimension.

Step 2   Review columns 3, 4, and 5. Decide how to evaluate participation in your organization. Write down what you will look for (column 3), who you will ask (column 4) and what documents you will search (column 5) to find out whether the organization is meeting criteria in each dimension.

For example, you may say that you will interview participants to evaluate whether there are diverse participation activities and respectful, flexible and inclusive processes. The criteria and indicators will help you make an interview guide that will help you decide what to ask participants. Questions in an interview guide may look like this:

- What kinds of things are people doing to participate in planning and evaluating services?
- How are decisions made?
- Are participants' ideas valued, recognized and documented?
- How often are ideas of participants used?
- How are participants given the chance to use their skills?
- To what extent do participants have skills that are similar or different from each other?
- What is it like for the participants to work with the other members of the team?
- What is the leadership like?
- What is it like to attend meetings?

Using the criteria and indicators you will also write down what to look for when evaluating organizational documents. Documents can show you whether policies support diverse participation activities and respectful, flexible and inclusive processes. Examples of what you would look for in documents are statements about whether the organization:

- Believes it is important for people to participate
- Is committed to making decisions with others
- Uses plain language
- Makes sure that information about people is confidential
- Believes that there should be no prejudice or discrimination

Step 3 Conduct the evaluations by conducting interviews and reviewing documents.

Step 4 Analyze results. Identify areas of strength and weakness. What criteria are being met? Where are there gaps?

Step 5 Share the results within the organization.

Step 6 Develop and implement an action plan to address gaps.

Terms

Citizen-user - The term "citizen-user" identifies people who need mental health services. The term says that people have rights as citizens and experiences of using services in the mental health system.

Consumer representatives – These are people who represent consumer and self-help groups.

Health planners – These are the people who make decisions about the funding and delivery of programs and services. They work for governments, health authorities and hospitals.

Non-consumer staff – These are the people deliver programs and services and do not identify as being consumers of mental health services.

Policies – Most organizations have policies. Policies are written statements that guide decisions and actions of organizations. They often describe principles and values of the organization.

Committee documents – Most organizations have committees and working groups that address issues about the planning, quality and evaluation of programs and services. These committees have documents including terms of reference, records of meetings and correspondence. Terms of reference describe the purpose of the committee, who should attend, authority, responsibility and how often the committee meets. Records of meetings include agendas and minutes. Correspondence includes letters and e-mails.

Accreditation documents – Most health organizations go through an accreditation process. In this process an outside organization rates how well the health organization is doing against many criteria. This is one way that the quality of the services provided by the health organization is evaluated. The health organization has reports and other written material related to this accreditation process.

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization provides opportunities for diverse participation activities.	Citizen-users participate in health service planning in several different ways.	**Look for:** • Statements that show participation activities are important to the organization. • Statements that show that participation activities occur. • Statements that show that citizen-users are asked what types of participation activities should be used. • Citizen-users have ways to give input into service planning without being asked or being part of formal committees.	**Ask:** Citizen-users Consumer representatives Health planners Non-consumer staff	**Look in:** Policies related to participation activities Committee documents

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization provides opportunities for diverse participation activities.	Citizen-users are involved at all four stages of health service system planning: - conceptualization - development - implementation - evaluation	**Look for:** • Documentation of participation activities in each of the four stages.		**Look in:** Committee documents Health service planning reports.
	Citizen-users discuss ideas and decisions about services with health planners.	**Look for:** • Statements that show citizen-users and others perceive that citizen-users and health planners discuss ideas and decisions.	**Ask:** Citizen-users Health planners Non-consumer staff	**Look in:** Policies related to participation activities Accreditation documents Committee documents

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization uses respectful, flexible and inclusive processes.	The organization uses plain language when communicating with citizen-users.	**Look for:** • Statements that plain language must be used during communication with citizen-users. • Proof that an analysis of the reading level of written material has occurred. • Statements that show that citizen-users feel that plain language is used during communication and in written material.	**Ask:** Citizen-users	**Look in:** Organizational policies related to participation activities Correspondence with participants Committee documents
	The goals of participation activities are agreed to by citizen-users and health planners.	**Look for:** • Statements that show that goals of participation activities were agreed to by everyone involved. • Whether the type of participation activity allows the level of citizen participation that is expected by citizen-users and health planners.	**Ask:** Citizen-users Health planners	**Look in:** Committee documents

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization uses respectful, flexible and inclusive processes.	Rules about how discussion occurs during participation activities are decided by citizen-users and health planners.	**Look for:** • Statements that show that the rules of discussion during participation activities are agreed to by everyone involved.	**Ask:** Citizen-users Health planners	**Look in:** Committee documents
	Citizen-users believe their opinions are valued by others involved.	**Look for:** • Statements that show that citizen-users believe that their opinions are valued.	**Ask:** Citizen-users	

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization uses respectful, flexible and inclusive processes.	The contributions of citizen-users are recognized.	**Look for:** • Statements that show citizen-users perceive that their opinions are recognized. • Documents that acknowledges the importance of the participation of citizen-users.	**Ask:** Citizen-users	**Look in:** Committee documents
	The organization accurately documents the ideas of citizen-users.	**Look for:** • Statements that show that the ideas of citizen-users are accurately documented.	**Ask:** Citizen-users	**Look in:** Committee documents

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization uses respectful, flexible and inclusive processes.	Action that has a positive impact on the health care system is an outcome of participation activities.	**Look for:** • Evidence that the information collected during participation activities is included in the development of programs and services.	**Ask:** Citizen-users Health planners Non-consumer staff members Consumer Representatives	**Look in:** Evaluation reports Research reports Quality reports Management meeting records
	The organization utilizes the skills of the citizen-users.	**Look for:** • Statements that show citizen-users are asked about their skills. • Evidence that position descriptions acknowledge varying skills. • Statements that citizen-users perceive that their skills are utilized.	**Ask:** Citizen-users	**Look in:** Committee documents Position descriptions

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization uses respectful, flexible and inclusive processes.	All those involved in the participation activities maintain confidentiality of personal information.	**Look for:** • Policies that explicitly state that confidentiality of personal information will be maintained.	**Ask:** Citizen-users Health planners Non-consumer staff	**Look in:** Policies
	A team approach is used throughout the participation activity process.	**Look for:** • Policies that affirm the use of a team approach. • Statements that show citizen-users and others perceive that they are part of a team during participation activities. • Standardized assessment of team functioning	**Ask:** Citizen-users Health planners Non-consumer staff members	**Look in:** Policies

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization uses respectful, flexible and inclusive processes.	Leadership is effective throughout the participation activities process.	**Look for:** • Statements that show citizen-users and others perceive that participation activities have effective leadership. • Evidence that shows that there are opportunities for leadership development. • Standardized assessment of team functioning	**Ask:** Citizen-users Health planners Non-consumer staff members	**Look in:** Leadership training manuals.
	People with diverse experiences are included.	**Look for:** • Evidence that shows that citizen-users have a variety of skills and experiences. • Statements that show citizen-users and others perceive that people with diverse experiences are included in the participation activity.	**Ask:** Citizen-users Health planners Non-consumer staff members Consumer Representatives	**Look in:** Committee documents Position descriptions

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization uses respectful, flexible and inclusive processes.	Meetings are scheduled taking into consideration citizen-users' schedules, safety and comfort.	**Look for:** • Evidence that meeting times are negotiated with citizen-users. • Evidence that citizen-users perceive that their schedules and safety are considered when developing meeting times. • Evidence that the environments in which meetings take place are comfortable for citizen-users	**Ask:** Citizen-users	**Look in:** Committee documents
	The people who run the meetings conduct them in ways that are comfortable for the citizen-users.	**Look for:** • Statements that show citizen-users perceive that meetings are comfortable.	**Ask:** Citizen-users	

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization uses respectful, flexible and inclusive processes.	Processes are free from intimidation, exploitation and discrimination.	**Look for:** • Policies denouncing intimidation, exploitation and discrimination in all organizational forums. • Evidence that there are mechanisms for participants to address behaviour perceived as intimidation, exploitation or discrimination. • Evidence that participants are informed of mechanisms to address behaviour perceived as exploitation or discrimination. • Statements that the participation of citizen-users will not impact negatively on the type or amount of health services they can receive from the organization.	**Ask:** Citizen-users	**Look in:** Policies Orientation packages

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization supports citizen-users throughout the participation process.	Citizen-users receive training.	**Look for:** • Evidence that training is offered and attended by citizen-users.	**Ask:** Citizen-users Health planners Non-consumer staff members	**Look in:** Policies Records of training programs Evaluation of training programs
	Citizen-users have sufficient information to fully participate.	**Look for:** • Proof that citizen-users are provided with orientation packages prior to the participation activity. • Written acknowledgement of the need to keep citizen-users informed. • Evidence that shows there are processes in place to keep citizen-users informed. • Statements that show citizen-users perceive that they have sufficient information to participate.	**Ask:** Citizen-users	**Look in:** Committee documents Orientation packages Training modules

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Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization supports citizen-users throughout the participation process.	Information provided to citizen-users is provided in a way that is understandable and useable.	**Look for:** • Written acknowledgement that the organization needs to provide information in a way that is understandable. • Statements that show citizen-users perceive that they understand the information provided to them. • Statements that show citizen-users perceive that they can use the information provided to them. • Statements that show that the ways that information is provided to citizen-users is evaluated.	**Ask:** Citizen-users	**Look in:** Policies

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization supports citizen-users throughout the participation process.	Citizen-users receive encouragement and guidance from staff and management.	**Look for:** • Statements that show citizen-users perceive that they receive encouragement and guidance. • Written expectations that staff and managers will provide encouragement and guidance to citizen-users.	**Ask:** Citizen-users	**Look in:** Policies
	Citizen-users receive resources and supports for advocacy and self-advocacy.	**Look for:** • Training modules that include advocacy and self-advocacy. • Statements that show citizen-users are given information about the resources and supports for advocacy. • Money is available to help new and existing advocacy groups to participate.	**Ask:** Citizen-users	**Look in:** Committee documents Training modules Policies Budgets Annual reports

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization supports citizen-users throughout the participation process.	Citizen-users are remunerated for their participation.	**Look for:** • Ways that remuneration for time and transportation is offered to participants	**Ask:** Citizen-users Consumer representatives	**Look in:** Policies Budgets
	A budget is provided for participation activities.	**Look for:** • An allocated budget for participation activities.		**Look in:** Policies Budgets Annual reports
The organization promotes citizen-user participation in the decision making process.	Citizen-user participants have similar characteristics to the population impacted by planning decisions.	**Look for:** • A policy that supports representativeness. • Ways that the demographic characteristics of the population impacted by planning decisions are documented. • Statements that show that citizen-users and others perceive that participants are representative of the population.	**Ask:** Citizen-users Consumer representatives Health planners Non-consumer staff members	**Look in:** Policies Documentation of the demographic characteristics of the population impacted by decisions

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization promotes citizen-user participation in the decision making process.	The interests of the population impacted by planning decisions are represented in participation activities.	**Look for:** • Ways that interests are discovered and documented. • Statements that show citizen-users and others perceive that the interests of the affected population are represented.	**Ask:** Citizen-users Consumer Representatives Health planners Non-consumer staff members	**Look in:** Planning documents
	There are multiple ways that people are informed about opportunities for participation.	**Look for:** • Ways that information about opportunities for participation is provided through word of mouth, public service announcements and posters in community locations. • Statements that show that plans are made for changes to the membership of committees and planning groups so that opportunities are available for more citizen-users.	**Ask:** Citizen-users Consumer Representatives Health planners Non-consumer staff members	**Look in:** Records of recruitment

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization clearly connects citizen-user participation to the decisions it makes.	The organization clearly describes and shares information with citizen-users and other stakeholders about the impact of participation activities on health system planning.	**Look for:** • Statements that show there is a clear plan for sharing information about decision making. • Ways that organizations use participation activities to make decisions. • Ways that organizations tell participants, citizen-users and other stakeholders how they used participation activities to make decisions. • Ways that organizations tell the public at large about the outcomes of their participation activities.	**Ask:** Citizen-users Consumer representatives	**Look in:** Evaluation reports Committee documents Organizational records including management meeting records, board minutes, and annual reports Public news releases and media reports

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization clearly connects citizen-user participation to the decisions it makes.	Responsibility for using the results of participation activities is clearly defined.	**Look for:** • Statements that show job descriptions describe responsibility for creating, conducting and evaluating participation activities. • Statements that show that accountability for linking participation activities to decisions is identified in position descriptions of key decision makers.		**Look in:** Position descriptions Performance appraisal forms

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization clearly connects citizen-user participation to the decisions it makes.	The organization evaluates participation activities.	**Look for:** • Evidence that resources are allocated for evaluation of participation activities. • Evidence that evaluation is done by someone who is not part of the participation activity or decision making. • Evidence that evaluation reports on the outcomes of participation activities are completed. • Policies that describe the goals, objectives and expected outcomes of participation activities. • Policies that mandate a review of participation activities on a regular basis.	**Ask:** Citizen-users Health planners	**Look in:** Committee documents Organizational records including management meeting records and Board minutes Policies

Dimension	Criteria	Indicators	Evaluation of Experience	Evaluation of Documents
The organization clearly connects citizen-user participation to the decisions it makes.	The organization continues effective participation activities.	**Look for:** • Plans to continue effective participation activities. • Plans to modify ineffective participation activities. • Plans for new participants to become involved in effective participation activities over time.		**Look in:** Committee records Organizational records including management meeting records and Board minutes Policies

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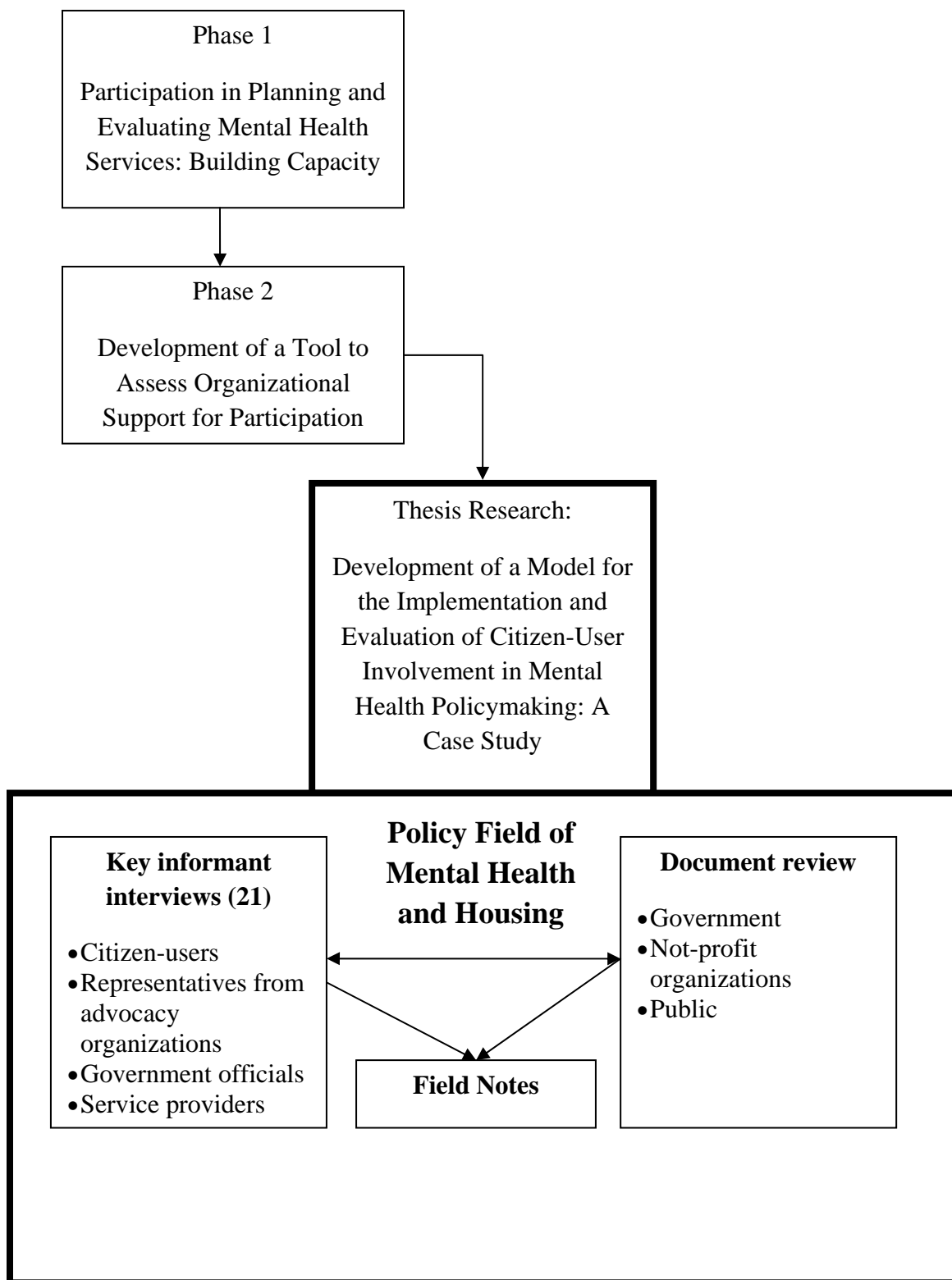
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Appendix F

Thesis Design

Phase 1

Participation in Planning and Evaluating Mental Health Services: Building Capacity

Phase 2

Development of a Tool to Assess Organizational Support for Participation

Thesis Research:

Development of a Model for the Implementation and Evaluation of Citizen-User Involvement in Mental Health Policymaking: A Case Study

Policy Field of Mental Health and Housing

Key informant interviews (21)

- Citizen-users
- Representatives from advocacy organizations
- Government officials
- Service providers

Document review

- Government
- Not-profit organizations
- Public

Field Notes

Appendix G

Recruitment Letter

Dear

I am writing to invite you to participate in an individual interview as part of the research project *Development of a Model for the Implementation and Evaluation of Citizen-User Involvement in Mental Health Policy: A Case Study*. The purpose of this research is find better ways to include people who use mental health services in developing health and social policies. By policies we mean the decisions and actions taken by public bodies, such as governments or health authorities, to address problems. In this study we are interested in understanding more about how people are involved in decisions about mental health and housing. We would like to study documents related to these decisions. We also want to hear from people who make the policies, people who implement policies and people who are affected by policies. We are seeking people who have been involved in policy discussions related to mental health and housing in Manitoba within the past year. We want to know what people involved in mental health and housing policies think about:

- the involvement of people who are affected by policies in policy development,
- what the outcomes of involvement should be and,
- what types of factors affect outcomes.

The interview will take about one and a half hours. A member of the study team will interview you. You will be asked questions about how people who use mental health services can be involved in developing policies. The interview will be recorded on an audio-tape recorder. The interviewer will also take notes to ensure that all of your ideas are included. Your identity will be not be revealed in reports or public presentation related to the study.

If you participate in this study on your own time, you will receive $25.00 for each interview that you complete to assist you in covering costs such as your time and transportation. If you participate on work time, as authorized by your employer, you will not receive compensation. All participants will receive a $10.00 gift certificate to a local

coffee shop as a token of appreciation for their participation. There are no other costs to you to participate.

If you would like to participate in this study or require more information please contact me at phone: 975-7736 or e-mail: g_restall@umanitoba.ca. Thank you for your interest in this project.

Sincerely,

Gayle Restall, MSc., BMR(OT)

Recruitment Poster

Citizen-User Involvement in Mental Health Policy

Your Ideas Are Valuable To Us

We are doing a study to find out how people who need mental health and housing services could be involved in making policies about services.

We want to hear from you if you have needed mental health and housing services in the past year.

We want to hear your ideas about
- the involvement of people who are affected by policy development,
- what the outcomes of involvement should be and,
- what things affect the outcomes of involvement.

To find out more about the study please contact Gayle at: 975-7736

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

<u>**Title of Study:**</u> Development of a Model for the Implementation and Evaluation of Citizen-User Involvement in Mental Health Policy: A Case Study

Principal Investigator:	Co-Investigator:
Gayle Restall	Dr. Joseph Kaufert
PhD Candidate	Professor
Department of Community Health Sciences	Department of Community Health Sciences
Faculty of Medicine	Faculty of Medicine
University of Manitoba	University of Manitoba
R106 - 771 McDermot Avenue	S 113 – 750 Bannatyne Avenue
Winnipeg, Manitoba R3E 0T6	Winnipeg, MB R3E 0W3
(204) 975-7736	(204) 789-3798

You are being asked to participate in a research study. Take your time to review this consent form and decide whether you would like to participate in this study. Ask any questions you may have of Gayle Restall or her research assistant (study staff). You may discuss the study and the consent form with your family, friends, or anyone else, before you decide. Please ask the study staff to explain any words or information in this consent form that you do not understand.

<u>**Purpose of Study**</u>: The purpose of this research is find better ways to include people who use mental health services in developing health and social service policies. By policies we mean the decisions and actions taken by public bodies, such as governments or health authorities, to address problems. In this study we are interested in understanding more about how people are involved in decisions about mental health and housing. We would like to study documents related to these decisions. We also want to hear from people who make the policies, people who implement policies and people who are affected by policies. We want to know what people involved in mental health and housing policies think about:

- the involvement of people who are affected by policies in policy development,
- what the outcomes of involvement should be and,
- what types of factors affect outcomes.

Study Procedures: You are being asked to participate in an individual interview. Prior to the interview, you will be asked to provide information about yourself such as your age category, gender and your experience with mental health and housing services. This information will be used by study staff to help make sure that people from different backgrounds and experiences are included in the study.

The interview will take about one and a half hours. A member of the study team will interview you. You will be asked questions about how people who use mental health services can be involved in developing policies. The interview will be recorded on an audio-tape recorder. The interviewer will also take notes to ensure that all of your ideas are included. Tapes will be transcribed later into a type-written document. Tapes, interviewer notes and any information identifying you that was collected for the purposes of this study will be destroyed 7 years after the end of the study.

You will receive a draft report that will summarize our findings. You will have the opportunity to respond to the report with any comments you may have. These comments will be taken into consideration in the final report.

You may be contacted for a second interview. The purpose of the second interview will be to clarify information provided in the first interview, ask more questions related to the study that arose from speaking to other people, or to ask for your opinions about how we interpreted our findings.

Risks and Benefits: There are no known risks to participating in this study. We hope the information learned from this study will benefit people who use mental health services.

Costs and Payment for Participation: If you participate on your own time, you will receive $25.00 for each interview that you complete to assist you in covering costs such as your time and transportation. If you participate on work time, as authorized by your employer, you will not receive compensation. All participants will receive a $10.00 gift certificate to a local coffee

shop as a token of appreciation for their participation. There are no other costs to you to participate.

Confidentiality: Information gathered in this research study may be published or presented in public forums. Your identity will not be revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. The University of Manitoba Health Research Ethics Board may review information gathered during this study for quality assurance purposes.

All records will be kept in a locked secure area and only study staff will have access to these records. You will be assigned study code that we will use on your records, instead of your name, to help protect your identity.

Voluntary Participation: Participation in this research is voluntary. You may stop participating in the study at any time. If you have any concerns during your participation in the interview we encourage you to talk about this with the interviewer.

If you decide not to participate, or to stop participating in the study, your employment or your ability to access or use mental health or housing services will not be affected.

Questions: If you have any other questions during or after the study, contact Gayle Restall at (204) 975-7736. If you have questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions of the study staff and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I discussed this study with Gayle Restall or her study staff. I have had my questions answered in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to stop participating at any time. I understand that information regarding my personal identity will be kept confidential, but that confidentiality cannot be guaranteed. I permit the University of Manitoba Research Ethics Board, to review information collected about me for this study, for quality assurance purposes. By signing this consent form, I have not given up any of the legal rights that I have as a participant in a research study.

I agree to be contacted for future follow-up in relation to this study,

Yes _____ No _____

I freely agree to participate in this research study.

Participant signature _____ Date _____

Participant printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____ Date _____

Signature: _____ Role in the study: _____

Development of a Model for the Implementation and Evaluation of Citizen-User Involvement

Appendix J

Participant Background Information Form

What is your age in years?   ☐ Under 21   ☐ 36-50   ☐ 21-35   ☐ 51- 65   ☐ over 65
What is your gender?   ☐ male   ☐ female
Which of the following best describes your involvement in mental health and housing policy?   ☐ someone who needs mental health and housing services (e.g., client)   ☐ a government employee   ☐ a representative of an organization that provides advocacy on behalf of people with mental illness   ☐ someone who provides services to people with mental health and social housing needs   ☐ other   Please specify   _____
What phrase best describes the amount of involvement you have had with mental health and housing policy?   ☐ very little   ☐ some   ☐ quite a bit   ☐ a lot

Appendix K

Interview Guide

1. Please describe your experiences with mental health and housing policy development. Probe: How have you felt about these experiences?

2. What does "involving people who use mental health services in health and housing policy" mean to you?

3. What ways are people who use mental health services currently involved in health and housing policy?

An involvement mechanism is something that governments do to intentionally involve people who use services in decision making.

4. What do you see as the important purposes of involvement mechanisms related to mental health and housing policy?

5. What are the potential outcomes of involvement to organizations and to individuals (positive, negative, and unintentional)?

6. Take a moment to think about all of the people who may take part in an involvement mechanism on mental health and housing policy. Who are the most important and why?

Policy decisions about mental health and housing take place within a context. Context includes all the factors that may affect what happens to the input that people provide into policy development.

7. What factors are important in determining the influence that people who use services have on mental health and housing policy decisions? Probe: types of factors: political landscape, history, organizational, participant

8. How do these factors influence policy decisions?

9. Is there anything about the policy issue of mental health and housing, in comparison with other mental health policy issues, that creates opportunities for more or less involvement by people who use services?

10. Given the complexity of making mental health and housing policy decisions, what is one message that you would give to governments about involving people who use services?

11. Is there anything else you would like to say about the involvement of people in mental health and housing policy?

Documents Reviewed

Document	Rationale for Inclusion
Canadian Collaborative Mental Health Initiative Final Evaluation	• Provided a national perspective of an initiative focusing on professional collaboration but with some reference to collaboration with mental health consumers.
Canadian Collaborative Mental Health Initiative Provincial Consultation Final Report	• One of the consultations was done in Manitoba providing a local perspective relevant to the case study. The consultations focused on advancing collaborative mental health care consistent with a principle of inclusiveness for mental health consumer interests.
Canadian Mental Health Association Winnipeg Housing Task Force Final Report	• Provided a local perspective on housing issues for people living with mental illness.
Canadian Mental Health Association National Backgrounder on Housing and Mental Illness	• Provided a national perspective on issues of housing and mental illness.
From Knowledge to Action (June 2008)	• Documents were generated from a forum sponsored by Legal Aid Manitoba, the

	Canadian Mental Health Association – Winnipeg, and the Manitoba Schizophrenia Society. The documents provided policy information relevant to mental health and social housing including potential strategies to address the policy issue.
Housing and Supports for People with Mental Illness: Provincial Advisory Committee on Mental Health Housing and Related Support Services (June 2008)	• Provided an example of an involvement mechanism related to the policy issue convened by the Manitoba Government that had a citizen-user representative.
Consumer Participation in Mental Health Services Planning, Implementation and Evaluation (policy) (2003)	• Provided information related to the Manitoba Government's commitment to consumer participation.
Mental Health Commission of Canada Research Demonstration Project (September 2008)	• Provided an example of an initiative to address the policy issue within the local context because Winnipeg was chosen as a demonstration site.
Winnipeg Regional Health Authority Mental Health Advisory Council Report 2005-2006	• Provided an example of a report from an involvement mechanism that engaged citizen-users in discourse about mental health service and policy.

Winnipeg Regional Health Authority Mental Health Advisory Council Report 2006-2007	• Provided a second example of a report from an involvement mechanism that engaged citizen-users in discourse about mental health service and policy that also included a specific section related to housing.