

COMMUNITY-BASED PUBLIC PARTICIPATION IN HEALTH CARE DECISION-MAKING AND PRIORITY-SETTING: APPROACHES IN CANADA AND AROUND THE WORLD

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SEPTEMBER 2006

Introduction

Ontario is undertaking significant reforms of its health care system by implementing Local Health Integration Networks (LHINs) and developing a new overall health strategy. Community engagement is seen as a crucial element of these and other reforms. How can community members be involved in developing strategic priorities and planning? This backgrounder reviews promising approaches used throughout the world.

The Public Participation Spectrum

It can be useful to understand the different approaches to public participation by locating them on a spectrum. The International Association for Public Participation has developed a spectrum based on increasing degrees of public impact, communication, and control at five levels of participation: informing, consulting, involving, collaborating, and empowering. At one end of the spectrum, public engagement is uni-directional (from sponsor to public) and intended only to provide information. At the other end, the communication flow is bi-directional and decisions are either made collaboratively between the public and the sponsor or the public has ultimate decision-making authority. Given that public engagement approaches at the more collaborative and participatory end of the spectrum are less well known and garner the most interest from the Ontario government and community groups, the engagement methods reviewed below all fall closer to that end.

What Is Deliberation?

Most public engagement methods discussed below are premised on a commitment to deliberation prior to final decision-making on policy issues. More than a discussion of issues, deliberation provides an opportunity to:

1. go beyond voting on a subject by sharing views on it, including preferences;
2. generate and consider a wider range of options;
3. encourage proposals and options less motivated by self-interest;
4. increase the legitimacy and ease the implementation of the final decision by giving all involved a fair say; and
5. build capacity among participants.¹

Through deliberation, the public becomes informed about an issue, discusses options collectively, and arrives at arguably better conclusions. Critics suggest that proponents of deliberative approaches for participatory policy decision-making naively reduce the uneven power relations embedded in any group, especially in those discussing contentious issues, to the pursuit of a rational consensus around a common good. In addition, they challenge the assumed neutrality of information as a tool for deliberation. Nonetheless, deliberative approaches offer innovative forums for genuine public engagement.

Forms of Public Engagement in Planning

Citizens' Juries and Planning Cells

Citizens' juries and planning cells have their roots in the US and Germany and have been used around the world since the 1970s.² Just in the UK, more than 100 citizens' juries have been held on a wide range of topics, including health issues, and the approach has been recommended by the Institute for Public Policy Research, the King's Fund Policy Institute, and the Local Government Management Board.³ The Labour national government has also sponsored citizens' jury pilot projects and has promoted it as a possible method for wider citizen participation in public policy development.⁴ Key features include:

- Typically consists of 12-16 randomly chosen people to deliberate over several days on a particular policy-related issue.
- Their objective is to reach a "verdict" after hearing testimonies from witnesses who are subject matter experts and/or stakeholder representatives and after being given sufficient time to deliberate.
- Trained moderators and facilitators support the proceedings.

¹ Fearon, JD. Deliberation as discussion. In J. Elster (ed.), *Deliberative Democracy*, 44-68. Cambridge: Cambridge University Press, 1998

² Smith G, Wales C. Citizens' juries and deliberative democracy. *Political Studies* 48 (2000): 51-65.

³ See Delap, C. *Making Better Decisions*. London: Institute for Public Policy Research, 1998, pp. 20-1; and McIver S. *An Evaluation of the King's Fund Citizens' Juries Programme*. Birmingham: Health Services Management Centre, 1997.

⁴ Department of Environment, Transport, and the Regions. *Modernising Local Government: Local Democracy and Community Leadership*. London: DETR, 1998, pp. 25.

- The jury's decision and any recommendations made, usually in the form of a citizens' report, are given to the sponsoring body (e.g. government department or agency).
- The sponsoring body is required to respond to the decision and recommendations, although it is not necessarily committed to acting on the decision in full.
- The planning cell differs only slightly from the citizens' jury. They usually have more participants (approximately 25) who deliberate for a longer period of time.

Some strengths of this approach include:

- Deeper examination of issues.
- Promotes consensus building.
- Can be useful among ignored/marginalized communities.

Weaknesses could be:

- Requires much time and resources.
- Likely to be unrepresentative due to small group size.
- May inadvertently promote greater cynicism from public if sponsor is not committed to acting on recommendations.
- Without a very skilled moderator, the process could flounder.

Citizens' Panels

Citizens' panels tend to have more permanency, can have many more members, and deliberate over a potentially broad range of issues through a process similar to the citizens' jury (usually smaller citizens' panels) or through more conventional polling mechanisms such as mailed and telephone surveys (usually larger citizens' panels).

Citizens' panels are used throughout the world. Here are two examples:

- Since 1999, Glasgow City Council in Scotland has operated a Citizens' Panel of approximately 1,500 residents representing a broad cross-section of the city.⁵ To help it determine and evaluate public service delivery and strategic planning, the Council conducts regular deliberative polls of the Citizens' Panel, usually through face-to-face interviews. Panel membership usually lasts for 2 years. Similar citizens' panels are used throughout the UK.
- The European Citizens' Panel was launched in 2006 as a pilot-project in transnational public consultation rooted regionally.⁶ Ten regional panels of approximately 50 members each will deliberate on new directions for agricultural and rural development policies for Europe.

⁵ Glasgow Citizens' Panel. *Newsletter Issue 5*. Glasgow: Glasgow City Council. Also at: <http://www.glasgow.gov.uk/en/YourCouncil/CustomerInvolvement/Corporate/CitizensPanel/>

⁶ European Citizens' Panel. http://www.citizenspanel.org/press/index_en.html.

Some of this approach's strengths include:

- Longer-term, thus more institutionalized.
- Can be more representative.
- Can deliberate over a number of issues.
- Despite potentially larger group sizes, still employs deliberative methods.

Some potential drawbacks include:

- Very resource intensive.
- Require clear expectations and firm commitment from sponsor for genuine follow-up.
- Need to decide on best way to select/appoint/elect panel members.

Consensus Conferences

Developed in Denmark, consensus conferences typically involve a diverse group of “lay” citizens who deliberate on scientific or technical issues in dialogue with content experts. Usually two stages are involved – a first stage of small meetings with experts to discuss issues and reach consensus and a second stage of public presentation of findings usually open to the media.

Consensus conferences have been used throughout the world. Canadian examples include:

- Xenotransplantation in Canada (2001)
- Food irradiation (1989)
- Human genome (1989)
- Agriculture and genetic technologies (1987)

Strengths of this approach include:

- A good way to obtain informed opinions from lay persons on complex and highly technical issues.
- Provides a strong educational opportunity.

Drawbacks include:

- Resource intensive and may require multiple conferences for greater representation.
- Exclusive process that may not generate sufficient interest due to highly technical subject matter.
- May encounter problems in participant selection.

Deliberative Polling

Developed in 1988, deliberative polls go beyond conventional polling methods to incorporate a deliberative intervention between a first and second poll. Sample

sizes are usually large and randomly selected to increase representativeness. Deliberative polling methods can also be combined with citizens' panels to create a longer-term deliberative body that is relatively representative. Once a random sample of participants has been drawn and established, the procedure then involves the polling of participants (through the mail, phone, and/or face-to-face interviews), followed by discussion using various deliberative approaches (e.g. small/large facilitated group meetings), then a second poll.

Several large, significant deliberative polls have been conducted in recent years. Examples include:

- In the UK, regarding the future of the National Health Service.
- In Australia, regarding reconciliation with the aboriginal population.
- In Denmark, regarding the adoption of the Euro as a national currency.

Deliberative polling's strengths include:

- Can be more representative than smaller forums.
- Does not necessarily have to lead to consensus.
- Generates a representation of population informed opinions.
- Changes in responses can be observed after the deliberative intervention.

Potential drawbacks include:

- Very resource intensive.
- May miss the perspectives of ignored/marginalized communities.
- May simply reflect dominant as opposed to consensus perspectives.

Citizens' Dialogues

This approach has been used extensively in Canada since the mid-1990s. The procedure involves a sample of people usually of a hundred or more who work in small groups using a workbook or guide that contains general information about a particular issue. Participants are encouraged by a moderator to move from identifying values and consensus positions to suggesting concrete policy directions to address the issue.

Several Canadian examples of citizens' dialogues exist, including:

- Citizens' Dialogue on the Ontario Budget Strategy
- Citizens' Dialogue on the Future of Health Care in Canada
- Citizens' Dialogue on the Long-term Management of Used Nuclear Fuel.

Advantages of this approach include:

- A main and explicit objective is to develop concrete policy options.
- Small group deliberation within a large sample of participants has the advantages of both.

Some potential drawbacks are:

- Resource intensive.
- A lack of permanency.

Conclusion

Effective, practical public participation approaches that incorporate deliberation and that fall on the more collaborative end of the public participation spectrum are increasingly being adopted around the world. Indeed, recent evaluations in the UK have suggested the expansion of certain community engagement methods throughout the public sector.⁷

Still, despite these models' potential, their use by government agencies has been constructively criticized.⁸ Critics suggest that 1) the approaches have most often been utilized by state and related agencies to extract the public view without any concrete mechanism for follow-up and accountability; 2) that the processes have been largely driven by the state agencies and not communities themselves; and 3) that the processes have largely excluded the perspectives of historically marginalized communities. The settings, methods, and approaches implicit in the above public consultation mechanisms tend to reflect the preferences and cultures of mainstream sectors of society and are consequently often unintentionally exclusive of those "on the margins". Such a dynamic is likely to increase the inequality among differentially powerful groups. To address these failings and based on the results of an action research project⁹, researchers suggest that the consultation in deliberative approaches be "grounded"; that is, that:

- The discussion arises from within communities;
- A high level of commitment exists from the commissioners to the process and outcomes;
- The problem or question for debate is framed collaboratively;
- The process and resulting recommendations are context-specific and firmly located within the communities concerned; and
- Opportunities exist for longer-term community involvement.

⁷ See McIver S. *An Evaluation of the King's Fund Citizens' Juries Programme*.

⁸ Kashefi E, Mort M. Grounded citizens' juries: a tool for health activism? *Health Expectations* 7 (2004): 290-302.

⁹ Ibid.