Developing consumer-directed care for people with a disability: 10 lessons for user participation in health and community care policy and program development

Goetz F. Ottmann1,3 PhD, Senior Research Fellow
Carmel Laragy2 PhD, Lecturer

1UnitingCare Community Options–Deakin University, 221 Burwood Highway, Burwood, VIC 3125, Australia.
2RMIT University, GPO Box 2476, Melbourne, VIC 3001, Australia. Email: carmel.laragy@rmit.edu.au
3Corresponding author. Email: goetz.ottmann@deakin.edu.au

Objectives
User involvement in planning and policy decision making has become the policy of choice for government as well as health and social care service providers in most democratic countries.1–7 This makes a lot of sense. Indeed, a growing body of research evidence suggests that actively engaging users in the program and policy design process leads to better policy outcomes.5 Yet this transition to a more participatory and collaborative mode of program and policy design has been uneven. In many health and social care programs, public participation is often restricted to the operational level where users can only influence the service mix they receive and user input into program design and policy making is often minimal.4,7–12 This is understandable. The transition to a more participatory mode of program and policy development requires a fundamental shift in professional practice and takes time and sustained effort. Moreover, little guidance is available for those who aspire to a more active involvement of user groups in decision-making processes. The lessons outlined in this paper were designed to provide health and social care professionals with a practical guide for an active and ongoing inclusion of user groups.

Setting, participants and methodology
We derived the following 10 lessons from a longitudinal study conducted between 2003 and 2008. The study gave rise to a Consumer-Directed Care (CDC – see Box 1 for an overview) project for people with disabilities and their carers or families hosted by UnitingCare Community Options (UCCO), a subsidiary of the UnitingCare network, a large provider of aged and social care in Australia. A detailed description of this government-funded project has been published elsewhere.13,14 Because of the limited scope of this paper, only a very cursory summary of the project is given.

The project was constructed in three stages. The predevelopment stage (1) involved the identification of potential participants as well as the development of knowledge and infrastructure...
elements underpinning the participatory approach. Approximately 20 families caring for a son or daughter with a disability in their homes declared an interest in participating in the project. Eleven families were eligible and decided to take up the option. A gap analysis was undertaken and participants received detailed briefings about a variety of CDC models and approaches. Also, they were given the opportunity to meet with consumers of already established CDC projects. A Project Steering Committee was formed and two participant Working Groups were created to drive the development of policies and procedures as well as to design innovative housing solutions for people with disabilities. The development phase (2) involved the employment of a project officer, the development of policies and procedures, the integration of the project into UCCO’s overall operational and administrative infrastructure, the creation of informal support groups, the design of consumer feedback and evaluation processes, and the development of safeguards geared to protect and support participants. During the subsequent iterative, formative development phase (3) the program was fine-tuned and evaluated (3).

Fig. 1 provides an overview of the participatory methodology employed. Readers who would like to obtain a detailed description of the methodology, approach, and participants are referred to Ottmann, Laragy, and Damonze.13

Participatory methods in health and social care policy and program design

Community-based health care governance structures have been trialled in various guises since the 1950s.5 Still, until the mid 1990s, projects that draw on the preferences of end users to determine policy options remained confined to the realm of experimentation.4,5,11,12,15–18 More recently, however, policy makers in Europe and North America have embraced consumer choice as a key criterion to make health and social care service more flexible and responsive.19–21 As a result, user involvement has been mainstreamed and many of the governance structures within the administration of health and social care have been replaced by programmatic approaches that transfer to users more direct control over the services they receive.7,22–25 Box 2 provides a summary of useful US-focussed resources that have emerged in the social care context.

Problems, conflicts, constraints and lessons learnt

In this case study, agency staff followed a participatory, family-governed approach advocated by Michael Kendrick, a US-based human services consultant.26,27 It selected suitable participants, developed participatory relationships, clarified roles and relationships as well as the decision making process, provided staff training that emphasised the decisional capacity of clients, and provided management and support structures. The outcome of this endeavour was somewhat paradoxical. Whereas the process gave rise to an extremely flexible CDC model with which consumers are mostly satisfied, the model did not offer sufficient safeguards for some of these consumers and as a result created several complex dilemmas for the agency. In a nutshell, the organisation was under pressure from consumers to ‘cash out’ advisory services but had a duty of care to them. Consequently, it had to ‘bail out’ several families when they lost control of financial management. For a detailed description of the program, see Ottmann et al.13,14 The following 10 lessons are informed by the strengths and weaknesses of this approach.

---

**Box 1. Consumer-directed care – an overview**

Consumer-directed Care (CDC) is regarded by many as a means to empower consumers. It is a tool that gives individuals with disabilities the opportunity to develop the skills to maximise control of their lives and their environment. In this most advanced context, CDC means that people assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services received. The overarching theme in CDC is that people with disabilities ‘have the authority to make choices that work best for them, regardless of the nature or extent of their disability’ (National Institute On Consumer Directed Long-term Services 1996, in Kosciulek).
Users should be engaged in the design process as early as possible to generate the conditions for a more meaningful involvement.

This presupposes choosing a participatory approach that is appropriate for the issues to be addressed. Each participatory approach carries with it its own limitations. For instance, forums facilitating ongoing user involvement tend to consume substantial resources. Also, iterative and formative approaches, because they require substantial time commitment from participants are suitable only for projects that address issues salient to participants (see, e.g. Ottmann and Street[28]).

An open, inclusive communication style in conjunction with a good understanding of potential concerns and a careful framing of the policy issue is required to build trust and allow meaningful collaboration.

To build trust and meaningful collaboration with and among participants it is crucial to understand the issues and position of the various groups represented, to establish relationships, and to anticipate concerns. Equally important is the framing of the policy domain. This requires a structured approach that clearly spells out the limits of participatory input. Issues that may fall outside the scope of user input are likely to include equity of access, availability of programmatic safeguards, as well as more general factors that potentially undermine participants’ ability to fully participate in a program.

Successful user involvement in program and policy development hinges on the ability to balance research evidence, consumer preferences, political and administrative factors, as well as operational and funding constraints.

Research participants have to be made aware of the different factors and constraints that are produced by these domains in order to participate effectively. Transparent mediating processes and methodologies capable of effortlessly weaving together the various strands of evidence have to be developed. Standard participatory designs are often inadequate because they are not responsive to the specificities of the wider policy and organisational context.

Meaningful user participation requires ongoing commitment and support from management and key stakeholders.

The knowledge generated by project participants has to be translated into practice. If users are to be equal partners in the development process, significant support from senior management and key stakeholders is required endowing user voices with the necessary authority to be adequately represented within organisational and government environments.

For user preferences to translate into program options, effective knowledge transfer processes as well as cultural change strategies have to be in place.

User involvement in decision-making processes tends to challenge established administrative hierarchies as well as professional routines. As a result, user participation to be meaningful and result in desired outcomes it has to be accompanied by corresponding developmental and cultural change strategies within agencies. Although this is easily the most important aspect underpinning the effectiveness of user involvement, it is frequently neglected, leading to user participation that has little or no programmatic outcomes.

Effective user participation hinges on participants’ ability to make informed decisions and to articulate these in a variety of forums.

Effective participation often requires the development of a new knowledge base and leadership capacity. This may require substantial resources and time as well as the development of appropriate learning strategies that reflect the needs of participants.
Facilitating user participation in community care

A mix of experiential learning styles framed by plenty of contextual information, and open-ended workshops, seminars, and web-based resources providing more abstract information may be required.

**Decision-making in health and community care brings into play power differentials that have to be assessed and mediated**

Policy design for health and community care is a multilevel political negotiation process that is laden with power relations and conflicts of interest. Underlying power differentials play a crucial role in this process. Indeed, as Chung and Lounsbery point out ‘lack of reflection over power differentials can lead to disempowering outcomes even after achieving a seemingly participatory process’. Hence, the checking and mediation of power differentials and conflicting interests is crucial to ensure equitable outcomes.

**Collective governance and group processes may require significant community-building efforts to work effectively**

Much of the action research literature builds on a romantic ideal where communities come together effortlessly in a spirit of cooperation and sharing. However, in practice this may not be the case. Conflicting views and incompatible personalities may undermine the best-planned collective governance structure. In fact, group processes may require safeguards in the form of ongoing community development initiatives and conflict mediation.

**Project participation is likely to decline at various stages during a project that spans several years. If substantial consumer engagement is sought, resources have to be set aside to encourage participation during the latter stages of a project**

Participatory processes demand a great deal in terms of ongoing commitment from consumers and consumer enthusiasm can slump after the novelty of the program has worn off. The step-by-step negotiation process that inevitably follows the euphoria of becoming part of a new project can be experienced as tedious by participants. Hence, if group processes are at the core of a project and if extensive consumer engagement is sought, substantial resources have to be set aside to rebuild commitment during low engagement phases and especially during later stages of a program.

**Participatory approaches require exceptionally strong, multilevel project management skills**

User participation in policy and program design requires multilevel project management and expert skills that often exceed locally available resources. Additional expert knowledge can be brought in by involving stakeholders in reference groups. Also, partnership arrangements with local universities may be of benefit.

**Conclusion**

This article outlined 10 important lessons that are often overlooked when implementing participatory designs. They should help health and social care professionals to develop a participatory strategy for program and policy design. However, more complex projects seeking more ambitious outcomes will require the input of a team with experience in collaborative and participatory methods.

**Competing interests**

C. Laragy had no competing interests as she was never employed or funded by UnitingCare Community Options. G. Ottmann held a joint appointment with UnitingCare Community Options during periods of this project. His relationship with the research host agency did not influence the way research results were published in this paper.

**Acknowledgements**

The project was funded by the Department of Human Services, Victoria, Australia, and the evaluation was assisted by grants from The University of Melbourne and La Trobe University. Moreover, the authors thankfully acknowledge the contributions of Gillean Damonze and Michelle Haddon of UnitingCare Community Options.

**References**


394 Australian Health Review G. F. Ottmann and C. Laragy

Manuscript received 12 March 2009, accepted 18 February 2010

http://www.publish.csiro.au/journals/ahr