

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

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**Abstract.** This paper outlines 10 lessons derived from the development of a consumer-directed care program for families with disabled children in Melbourne, Australia. The following program elements proved to be of importance over the course of the development process: (1) research participants should be involved as early as possible; (2) 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; (3) various strands of evidence have to be woven together; (4) ongoing commitment and support from management and key stakeholders; (5) effective knowledge transfer and cultural change processes; (6) capacity building; (7) mediation of power differentials; (8) community building; (9) participant re-engagement strategies; and (10) solid project management skills.

**What is known about the topic?** User involvement in planning and decision making has become the policy of choice for government as well as health and social care service providers in most democratic countries. However, there are few examples highlighting key factors for successful user involvement.

**What does this paper add?** Based on a longitudinal review of a program developed with significant user involvement, this paper outlines 10 key requirements underpinning participatory strategies for project and policy design.

**What are the implications for practitioners?** Participatory methodologies are potentially complex, have to be meticulously planned and resourced, and have to be carefully managed. To meaningfully involve users in more intricate projects may require the input of experienced professionals.

## 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.<sup>1–7</sup>

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.<sup>5</sup> 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.<sup>4,7–12</sup> 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.<sup>13,14</sup> 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

### 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<sup>7</sup>).

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.<sup>13</sup>

#### *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.<sup>5</sup> 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.<sup>4,5,11,12,15–18</sup> 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.<sup>19–21</sup> 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.<sup>7,22–25</sup> 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.<sup>26,27</sup> 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

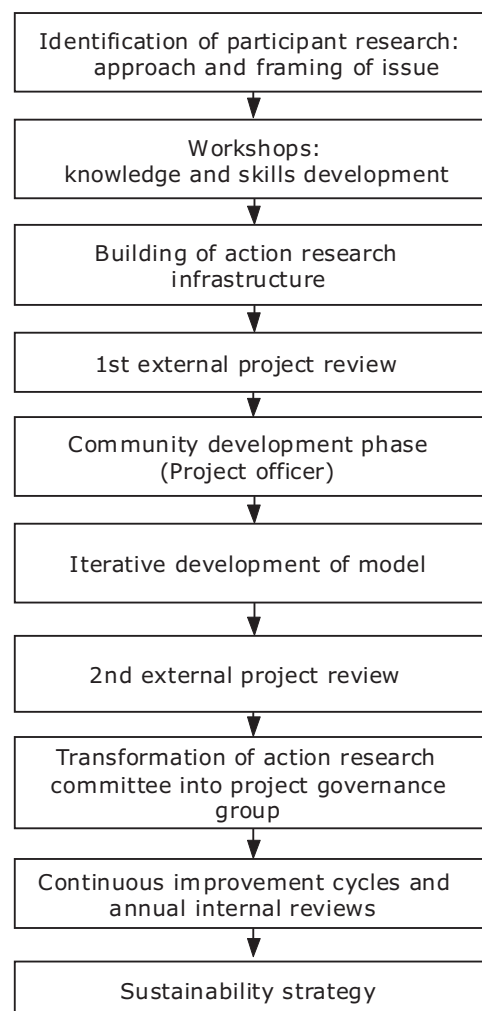


Fig. 1. CDC project overview.

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.*<sup>13,14</sup> The following 10 lessons are informed by the strengths and weaknesses of this approach.

**Box 2. Useful resources for practitioners**

- National Association of State Units on Ageing. More can be done: involvement of older consumers in the design, implementation, and oversight of home and community-based services. Prepared for the National Program Office for the Cash & Counseling Demonstration at Boston College; 2008. Available at <http://www.cashandcounseling.org/resources/20080303-111313> (accessed 30 September 2010)
- Holt J, Jones D, Petty R, Crisp S, Roth H, Galantowicz S. Facilitating Consumer Partnerships in State Policy and Program Design. Houston, TX: Independent Living Research Utilisation; 2007. Available at <http://www.hcbs.org/moreInfo.php/doc/2071> (accessed 30 September 2010)
- Bergman A, Ludlum C, O'Connor D, Starr J, Ficker TC. Stakeholder Involvement in Home and Community-Based Services: Roles in State Planning, Program Development, and Quality Improvement. Home and Community-Based Services Resource Network; 2002. Available at <http://www.hcbs.org/moreInfo.php/doc/150> (accessed 30 September 2010)
- Lomerson N, McGaffigan E, O'Connor D, Wambach K. When CPIGs Fly: Meaningful Consumer Involvement in Systems Change. Shrewsbury, MA: Center for Health Policy and Research, University of Massachusetts Medical School; 2007. Available at <http://www.umassmed.edu/uploadedFiles/CPIGS.pdf> (accessed 30 September 2010)
- University of Massachusetts, Center for Health Policy and Research. CPIGs Fly: Consumer involvement within the Massachusetts Real Choice and Independence Plus Grants [Final Report]. 2006. Available at [http://www.hcbs.org/files/101/5012/CPIGs\\_Fly\\_Consumer\\_Involvement.pdf](http://www.hcbs.org/files/101/5012/CPIGs_Fly_Consumer_Involvement.pdf) (accessed 30 September 2010)
- Roth H. Checklist for enhancing the participation and input of people with disabilities. Houston, TX: Independent Living Research Utilisation in collaboration with The MEDSTAT Group, Inc.; 2006. Available at [http://www.hcbs.org/files/96/4767/ILRU\\_ACCESS\\_CHECKLIST.pdf](http://www.hcbs.org/files/96/4767/ILRU_ACCESS_CHECKLIST.pdf) (accessed 30 September 2010)
- Long-term Care Authority of Tulsa. Effective public policy through shared vision, shared knowledge, and full participation of all stakeholders. 2003. Available at [http://www.hcbs.org/files/122/6092/Eff\\_PP\\_Publication.pdf](http://www.hcbs.org/files/122/6092/Eff_PP_Publication.pdf) (accessed 30 September 2010)
- Mosely C. The Guide: National Association of State Directors of Developmental Disabilities Handbook on Inclusive Meetings. Alexandria, VA: National Association of State Directors of Developmental Disabilities; 2006. Available at <http://www.nasddds.org/pdf/TheGuide.pdf> (accessed 30 September 2010)

*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<sup>28</sup>).

*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, for 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.

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.<sup>29</sup> Underlying power differentials play a crucial role in this process. Indeed, as Chung and Lounsbury point out 'lack of reflection over power differentials can lead to disempowering outcomes even after achieving a seemingly participatory process'.<sup>30</sup> 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 latter 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.

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## References

- 1 Department of Health. Our health, our care, our say: a new direction for community services (White Paper). Norwich, UK: Older People and Disabilities Division, Department of Health; 2006.
- 2 Administration on Ageing Choices for Independence: Modernizing the Older Americans Act. Washington, DC: Department of Health and Ageing; 2006.
- 3 Real Voices, Real Choices: the qualities people expect from care services. Newcastle, UK: Commission for Social Care Inspection; 2006.
- 4 Braye S. Participation and involvement in social care. In Kemshall H, Littlechild R, editors. User Involvement and Participation in Social Care. London: Jessica Kingsley Publishers; 2000.
- 5 Church J, Church J, Saunders D, Wanke M, Pong R, Spooner C, Dorgan M. Citizen participation in health decision-making: past experience and future prospects. *J Public Health Policy* 2002; 23(1): 12–32. doi:10.2307/3343116
- 6 Abelson J, Forest P-G, Eyles J, Smith P, Martin E, Gauvin F-P. Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. *Soc Sci Med* 2003; 57: 239–51. doi:10.1016/S0277-9536(02)00343-X
- 7 Kosciulek JF. Implications of consumer direction for disability policy development and rehabilitation service delivery. *J Disabil Policy Stud* 2000; 11(2): 82–9. doi:10.1177/104420730001100204
- 8 Kemshall H, Littlechild R. User Involvement and Participation in Social Care. London: Jessica Kingsley Publishers; 2000.
- 9 Parent W. Quality of life and consumer choice. In Wehman P, editor. The ADA mandate for social change. Baltimore: Brookes; 1993.
- 10 National Council on Disability. Achieving independence. *J Disabil Policy Stud* 1996; 7(2): 57–65. doi:10.1177/104420739600700204
- 11 Rowe R, Shepherd M. Public participation in the new NHS: no closer to citizen control? *Soc Policy Adm* 2002; 36(3): 275–90. doi:10.1111/1467-9515.00251
- 12 Baggott R. A funny thing happened on the way to the forum? Reforming patient and public involvement in the NHS in England. *Public Adm* 2005; 83(3): 533–51. doi:10.1111/j.0033-3298.2005.00461.x
- 13 Ottmann G, Laragy C, Damonze G. Consumer participation in designing community based consumer-directed disability care: lessons from a participatory action research-inspired project. *Syst Pract Action Res* 2009; 22(1): 31–44. doi:10.1007/s11213-008-9110-z

- 14 Ottmann G, Laragy C, Haddon M. Experiences of disability consumer-directed care users in Australia: results from a longitudinal qualitative study. *Health Soc Care Community* 2009; doi:10.1111/j.1365-2524.2009.00851.x
- 15 Butler C, Rissel C, Kharvarpour F. The context for community participation in health action in Australia. *Aust J Soc Issues* 1999; 34(3): 253–65.
- 16 Milewa T. Local participatory democracy in Britain's Health Service: innovation or fragmentation of a universal citizenship? *Soc Policy Adm* 2004; 38(3): 240–52. doi:10.1111/j.1467-9515.2004.00388.x
- 17 Milewa T, Dowswell G, Harrison S. Partnerships, power and the 'new' politics of community participation in British health care. *Soc Policy Adm* 2002; 36(7): 796–809. doi:10.1111/1467-9515.00318
- 18 Morone JA, Kilbreth EH. Power to the people? Restoring citizen participation. *J Health Polit Policy Law* 2003; 28(2–3): 271–88. doi:10.1215/03616878-28-2-3-271
- 19 Simmons R, Powell M, Greener I. The consumer in public service: Choice, values and difference. Bristol: Policy Press; 2009.
- 20 Diamond P. Public Matters: The renewal of the public realm. London: Politico's Publishing; 2007.
- 21 Glendinning C, Kemp PA. Cash and Care: Policy challenges in the welfare state. Bristol: Policy Press; 2006.
- 22 Glendinning C, Challis D, Fernandez J-L, Jacobs S, Jones K, Knapp M, et al. Evaluation of the Individual Budgets Pilot Program. Final Report. London: Social Policy Research Unit, Personal Social Services Research Unit, Social Care Workforce Research Unit; 2008.
- 23 Simon-Rusinowitz L, Mahoney KJ, Marks LN, Zacharias BL, Loughlin DM. The cash and counseling demonstration and evaluation: focus group inform design of a consumer directed cash option. *Care Manag J* 2005; 6(2): 56–65. doi:10.1891/cmaj.6.2.56
- 24 Tilly J. Recent research on consumer-directed home care in the Netherlands, England, Germany and the United States, outcomes. *Australas J Ageing* 2005; 24: S59. doi:10.1111/j.1741-6612.2005.00091.x
- 25 Ungerson C. Whose empowerment and independence? A cross-national perspective on 'cash for care' schemes. *Ageing Soc* 2004; 24: 189–212. doi:10.1017/S0144686X03001508
- 26 Kendrick M. The natural authority of families. *Crucial Times* 1996; 6 (July). Available at <http://www.socialrolevalorization.com/articles/kendrick/natural-authority-of-families.pdf> [accessed 4 October].
- 27 Kendrick M. Family-Governed Flexible Family Support: The Massachusetts Small Project Example. Working paper sponsored by Massachusetts Families Organizing for Change and Uniting Families for Change of Western Massachusetts. 2001. Available at <http://www.kendrickconsulting.org/pubreg.asp?pid=22&ptype> [accessed 4 October 2010].
- 28 Ottmann G, Street AF. Ten lessons for developing a health information website. *Aust Health Rev* 2007; 31(4): 523–6. doi:10.1071/AH070523
- 29 Shaw SE. Driving out alternative ways of seeing: the significance of neo-liberal policy mechanisms for UK primary care research. *Soc Theory Health* 2007; 5(4): 316–37. doi:10.1057/palgrave.sth.8700102
- 30 Chung K, Lounsbury DW. The role of power, process, and relationships in participatory research for statewide HIV/AIDS programming. *Soc Sci Med* 2006; 63(8): 2129–40. doi:10.1016/j.socscimed.2006.04.035

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