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Consumer Participation in Designing Community Based Consumer-Directed Disability Care: Lessons from a Participatory Action Research-Inspired Project

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Abstract   User participation has been embraced worldwide as a means to provide better consumer outcomes in health and community care. However, methodologies to achieve effective consumer engagement at the programme design level have remained under-explored. The purpose of this study was to evaluate the impact of a Participatory Action Research (PAR)-inspired methodology used to develop a consumer-directed community care/individualised funding service model for people with disabilities. A retrospective analysis of case notes and internal reports for the first 6 years of an ongoing project were examined. The findings suggest that PAR methodologies need to take into account community development, group support, and capacity building as well as succession planning and risk management issues in order to facilitate the often lengthy policy and project development process. Drawing on these findings, this article discusses five lessons and their methodological implications for PAR in a health or social policy/programme design context.

Keywords   Participation · Action research · Consumer-directed care · Community disability services · Policy development

Introduction

Empowerment of users of social care services has turned into a key issue in much of the current literature on social work and social policy. Calls for empowerment, participation

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and partnership are particularly strong in community care services for people with a disability where a growing belief has emerged that consumers of personal assistance services should exercise choice over the services they receive and, in the process, gain or regain a measure of control over their lives (Emener 1991; Bolton and Brookings 1996; Shakespeare 2006). At the governmental level, there is now increasing endorsement of consumer participation and partnership (Kosciulek 2000; US Administration on Ageing 2006; UK Commission for Social Care Inspection 2006; UK Department of Health 2006). Despite many projects being designed around principles of consumer self-determination and control, user involvement has often been restricted to the operational level where they can only influence the service mix they receive. Their influence on policy making or on agency decision-making at senior management level is often minimal (Parent 1993; National Council on Disability 1996; Kemshall and Littlechild 2000; Kosciulek 2000). Moreover, there is a dearth of studies that systematically evaluate methodologies that foster user engagement during the programme design and policy development phases. This article addresses this gap.

The article describes and critically evaluates the use of a participatory methodology in an Australian project developing a consumer-directed, community based disability services model. Over the course of the first 3 years, the process led to the development of a community care service model that satisfied most project participants. This article seeks to further our understanding of how participatory approaches can be used to involve consumers in human services policy and programme design.

Uniting Care Community Options (UCCO), a non-governmental agency providing case management to people who prefer to remain within the community, hosted the Consumer-Directed Care pilot programme. UCCO is a subsidiary of the Uniting Care network, a large Australian provider of community and residential care services attached to the Uniting Church. The study is based on a retrospective analysis of internal reports, minutes, newsletters, as well as two unpublished external evaluations covering the period between 2002 and 2008. UCCO approved the use of internal documents on the basis that the privacy of consumers and staff would be protected. Hence, names as well as personal details that would allow others to identify the people that contributed to this study have been deleted. Data recorded by the two unpublished reports has been used with the knowledge that the proposals preceding the evaluations were subject to a robust ethics review process.

Consumer-Directed Care

Consumer-directed Care (CDC) is regarded by many as a means to empower consumers.[1] In its most advanced form, 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 2000). According to Kosciulek (2000), CDC comprises four components:

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[1] Programmes based on the philosophy of CDC, a term that emerged within the North American context, are elsewhere known under names such as flexible funding, individualised funding, self-management, cash for care, and independent living.

1. Consumers control and direct services
2. Have access to a variety of service options
3. Have access to information and long-term supports that create personal, legal, and financial safeguards; and
4. Participate in policy making and have design and decision-making input (see also Braye 2000; Blackman 2007)

Hence, in its ideal form, consumer input into policy and decision-making as well as to programme design is at the core of the CDC approach.

In practise, however, the degree to which programmes allow for consumer direction in disability services varies substantially. Programmes vary in the way they allow for service components to be 'cashed out', the degree to which cash payments are determined by prescriptive care plans, and whether family members and particularly spouses can be hired as support staff (Ungerson and Yeandle 2007). Moreover, programmes differ in the way they offer information and support, facilitate access to a variety of service options, and enable families to participate in the development of policies and procedures (Phillips et al. 2003).

UCCO's Participatory Approach

In 2002, several families approached UCCO with the request to create individualised, person-directed support funding arrangements. With support from the agency, this request galvanised other UCCO-linked families searching for more flexible ways of managing their funding packages. As a result, in late 2002 UCCO contacted the Department of Human Services (DHS) with the request for additional funds to develop a family governed, individualised funding project for families caring for a family member with a disability eligible for specific government disability support. All eligible families were invited to information sessions. Over the following months, UCCO in conjunction with Michael Kendrick, a human services consultant, developed a family centred CDC plan shaped by family governed CDC projects in Massachusetts (Kendrick 2001). The motivating force for UCCO management was to give more control to consumers and to create greater flexibility as well as transparency regarding funding arrangements. Moreover, it was expected that CDC initiatives would reflect the passion and interests of people with disabilities in ways that are difficult to provide through the formal community service system.

A participatory methodology was central to the development of UCCO's CDC project. For UCCO's management it was important that the project would not only give families greater control over the services received, but also that families would design and run the project. To achieve this, UCCO management provided and facilitated capacity building and leadership development opportunities in conjunction with participatory structures that gave families the opportunity to run the project.

Table 1 provides an overview of the basic programme development steps as they were envisaged at the outset of the project.

UCCO assisted the families in forming a Project Steering Committee (PSC) and make executive decisions supported by a project officer when employed. The task of this steering committee was to:

– Formulate the vision and mission of the project
– Set priorities
– Discuss the parameters of the project
– Employ a project officer (writing of job description, interviewing, etc.)

Table 1 Programme logic overview of UCCO CDC project

Resource/Input	Activities	Outputs	Outcomes	Impact
Project Governance: Management Group External Consultant *Financial Governance:* UCCO/DHS *Leadership, support and strategic direction:* Steering Committee 2 Sub-committees, Project Officer *Implementation Site:* Melbourne's eastern region	Phase 1: Design of Pilot Service Model Development of pilot service model (iterative, formative, participatory methodology) Phase 2: Implementation of Service Model Implementation and refinement of service model Evaluations Qualitative Evaluation at two time points ($T + 6$, $T + 36$ and $T + 48$)	Governmental and institutional support for project. Draught implementation model. Administrative infrastructure for model, Formal and informal consumer mentoring system in place, Functional participatory infrastructure Documented evidence of programme effectiveness.	A flexible consumer-directed service model for people with disabilities and their carers. Identified key components that need to be in place for successful implementation. Effectiveness of pilot service model is demonstrated	More flexible service response to needs of care recipients, families, and/or carers resulting in better quality of care. Significant reduction of service gaps & unmet service needs. Consumers and carers exercise choice over services and service delivery modes. High user satisfaction with service model.

- Make decisions regarding the spending of funds
- Explore and implement ways to increase the knowledge and skills of families, and
- Organise social gatherings

In addition, UCCO encouraged the establishment of two sub-committees: A consultant-supported sub-committee charged with the development of policies and procedures that were to underpin the CDC project and a housing sub-committee working towards innovative housing solutions for people with disabilities.

UCCO also fostered knowledge and capacity building activities. All families receiving services through the agency were invited to participate in a series of workshops, conferences, seminars and internal meetings that communicated the basis of person-centred care, social role valorisation, as well as consumer-directed care. Each of the 15 families involved in the pilot project was invited to attend a series of workshops led by Michael Kendrick. These workshops provided an introduction to a range of CDC modalities. Moreover, families had the opportunity to meet participants of already established CDC projects in Australia. These knowledge and capacity building programmes encouraged families to break the mould of formal support services and they were encouraged to think of new and creative ways to address their needs. Moreover, UCCO supported a group geared to improving the planning skills of families. This group successfully applied for external funding and delivered a series of workshops.

Results

The PSC first met in July 2003 to develop policies and guidelines for the project. It consisted of seven family members, one of whom was already self-managing a larger amount of funding. One of its first decisions was that policies and procedures should be drafted before families could commence with the programme. As a result, families only began to manage their care services from March 2004 onward (by July 2004, all 13 families were self-managing). Moreover, the PSC decided that funds would not be pooled or distributed unevenly on a needs basis as was practised by several individualised funding, family governed projects in Massachusetts (Kendrick 2001). Rather, families were to individually manage the funding allocated to them. It also emerged that most families did not want to take on the administration of the support packages and agreed that UCCO was to retain 10% of the value of the packages to cover administrative expenses. The families would decide how to use the remainder of the package. Assistance was provided by the project officer for the first 2 years and informal mutual support networks were encouraged. Also, the term 'individualised funding', used in UCCO's original proposal, was replaced by the PSC with 'self-management'. This term highlights the value families placed on self-determination. Indeed, 'self-management' became the overarching goal of the programme.

Participatory Relationships

It emerged early on that the project's terminology was interpreted in a variety of ways by the participating families. For instance, 'self-management' and 'family governance' meant different things to different people. Some families, encouraged by workshops with Michael Kendrick (Kendrick 1996), regarded 'family governance' as a collective enterprise where key policy and procedural decisions would be made jointly together with other families. Others simply saw it as an opportunity to self-manage their own funds and they were not

interested in lengthy group meetings. Perhaps unsurprisingly, it was families belonging to the former group that gravitated towards the steering committee.

Families disagreed over the role and function of the steering committee. While PSC members saw it as their role to write a submission for extra funds to educate the community about disability issues and participate in legislative reform, other families considered that these broader activities distracted the Committee from its main task of advancing the work associated with the CDC programme. This frustrated families who were eager to commence managing their individual funds immediately. Hence, early on during the development phase, important differences began to emerge that would determine and shape the participatory relationship over the coming years.

For UCCO, the PSC was the main point of contact with the families. As mentioned above, the committee attracted families interested in a more collective approach. However, they were not representative of all voices (Laragy 2004). During September of 2003, the committee employed a project officer. Although physically located at one of UCCO's offices, the project officer primarily answered to the PSC. The project officer was to:

– Work alongside the steering committee to develop policies and protocols
– Support families during the uptake of CDC
– Act as a point of contact for families as well as UCCO case managers
– Encourage families with similar worldviews and interests to exchange ideas, and
– Meet with families to help them elaborate a vision and subsequently a plan for the people with disabilities in their care as well as for the wider family

Funded by DHS in the form of a start-up grant, the position of the project officer was initially limited to 1 year, but was extended by a further year. It was envisaged by UCCO management that, after this period, families would be able to manage the packages on their own making use of informal mutual support networks.

During the second half of 2004, the PSC was transformed into an all-inclusive Governance Group. This occurred when the project was expanded to include families receiving a range of 'packages' aside from Making a Difference funding. While the PSC was made up of seven family representatives, the Governance Group gave voting rights to all families involved at that time. It was expected by management that the Governance Group would make a wide range of decisions and deal with the expenditure of grant funding, purchasing of resources, as well as the presentation of papers at conferences. Moreover, it was envisaged that the Governance Group would take on co-ordination and support tasks and participate in project evaluations.

Although clearly more representative than the PSC, the, all-inclusive Governance Group accentuated different attitudes and personality clashes and its size proved to be unmanageable. The following statements by Governance Group members collected during the second half of 2004 articulate these tensions:

"I would like to see us work as a group (Family member in 2004)."

"A group of 5 or 10 would be great, 13 has been too big (Family member in 2004)."

"I don't hold much hope for the group unless we form smaller groups of people more alike in personality and interests. I would most probably withdraw form the group unless there is a change in the structure. I would like a group where there is a feeling of support, humour, optimism, and energy (Family member in 2004)."

"It's time now for one philosophy out of a lot of opinions (Family member in 2004)."

In a report drafted at the end of the project officer's tenure, she described the situation in the following terms:

In theory the governance group is a good idea. It would allow families to exchange information and give them a collective voice. It is a practical move from the PSC, so that all members have equal participation … However, there are clear personality clashes within the group, which distract from the work at hand. This may be in part because the group did not form naturally and therefore it is more like a work environment where you may not necessarily be working with people of your choice. It may also be that when you place 13 families together who have large demands on them, high stress levels and generally suffering from exhaustion that any group would clash. …The group should build people up not drain them. Presently this is not the case.

Management and Support

UCCO envisaged that families would share their growing expertise with other families in informal mutual support groups (referred to as informal groups below).

In her 2005 report, the project officer articulates this expectation:

Having worked closely with all these families for 2 years, I can testify to the fact that these families are near experts in a wide range of areas. If there were some way to effectively distribute all this information they would be well equipped.

Yet, the project officer also outlines the likely limitations of this informal support group strategy:

There are some areas in which the families still require support and information that they may not get from each other or other resource avenues …These include such things as being informed about when DHS will be taking [grant] applications, possible grant opportunities, UCCO equipment fund applications, movie tickets and Variety Club tickets.

Indeed, as the following statements by parents, collected by the project officer in 2005 demonstrate, many families were anxious about how they would be able to access the information, support and resources required to self-manage their support packages post the development phase:

"I don't feel confident because I think it needs a coordinator to pull it all together if it becomes one parent that pulls it together the burden can become too great."

"It would be good to know about any training that UCCO is offering to staff, there could be times when parents could attend. Or perhaps there is a speaker that parents would be interested in hearing."

"Let us know what other projects are doing in UCCO,… Great things happen but nobody knows about them."

"Who is going to apply for more funding?"

With the developmental phase concluding and the role of the project officer ending, a number of solutions to some of these concerns were worked out, which included:

- Families could buy additional services such as case management for advice and support
- Specialist training on how to procure additional funding for additional needs; and
- Recruitment services when they needed support workers

Moreover, families could contact the new Planning and Facilitator team for 'one-off' advice that did not require written responses. The Planning and Facilitator team would also provide several weeks of programme support, including assistance with the establishment

of service plans, for families new to the project. As the following statement shows, this clearly put the families at ease.

"It is reassuring to know that I can purchase case management. In certain situations the only way forward is to have access to a case manager. It's good to know that we are in the position to get one if we need one (Family member in 2005)."

Approximately half of the families decided to maintain a case management component, a service they now paid for from their packages. The others decided to purchase case management when needed. Whereas, in theory families could purchase case management from their allocated funds, in practise some of these families found that this could be difficult to obtain, due to operational constraints.

Interestingly, most families rejected UCCO's proposal to allocate funding to employ an ongoing project officer. This decision contributed significantly to the changes summarised below that undermined the collective support network of the project.

Participatory Relationships

During 2005, the Governance Group disintegrated and was finally disbanded because of growing internal tensions. With the break up of the Governance Group, families lost a vehicle that allowed them to be directly involved in the decision-making processes that was highly valued by UCCO management. No longer able to draw on an essential part of the infrastructure that allowed for consumer participation, UCCO had to find alternative means to manage the project. In part, UCCO resolved this by creating a staff position that took on a project officer function. Moreover, in the absence of a cohesive consumer group, this staff member became the 'administrator' of the project. Rather than focusing on community- and capacity-building, the project officer delegated many tasks to other inexperienced staff members, leaving working groups made up of supportive families without guidance and support. In other words, consumer involvement in the decision-making process did not end at this stage. However, communication between UCCO and the families became more ad hoc and certainly less family driven.

More importantly still, with the dissolution of the Governance Group, the informal support network strategy was seriously under threat. Although some informal groups did remain after the disintegration of the Governance Group (Laragy 2008), individual families had only limited access to this collective knowledge base. Newcomers (at the time of writing the project had 22 families) found it particularly difficult to access these groups. Perhaps unsurprisingly, families consistently identified access to information as one of the most important points that required attention (Laragy 2008). More importantly still, a significant number of families felt increasingly isolated and disconnected from social care networks. Several of these families found it more and more stressful and difficult to plan and direct the care for their relatives. Although some of these families did contact agency staff to ask for assistance, UCCO's internal processes proved insufficiently responsive to these requests. In fact, the full scale of the struggle of these families was only picked up by a routine internal review.

Furthermore, as families received information through a wide variety of sources they increasingly received conflicting and confusing responses. For instance, families who contacted DHS as well as UCCO for advice regarding funding frequently received contradictory information. This led several families to erroneously conclude that UCCO failed to provide services they were entitled to.

Role and Relationship Clarification

The drafting of a hosting arrangement to clarify the relationship, roles and responsibilities of UCCO and the families occurred early on. However, this document was never unanimously ratified by the families. It was later decided by UCCO and family representatives that the collective hosting agreement was to be substituted with individual hosting agreements giving each family members the opportunity to negotiate an agreement that corresponds to the family's needs. However, the negotiation process proved time-consuming and only two families had signed a hosting agreement at the time of writing. As a result, key issues, such as the extent to which families could obtain information from agency staff for free, were never formally settled and procedures were open for negotiation. As a result, expectations among families and among staff as to what UCCO would provide differed significantly.

In contrast to the hosting agreement, the relationships between families and paid carers were clearly defined early on. The policy and procedures sub-committee circulated a draught 'policies and procedures' manual as early as August 2004. This document focused on the recruitment of support workers, outlined what could be reasonably expected of them; defined the responsibilities of families; and it gave an overview of the enterprise bargaining agreement covering employment conditions. Moreover, the manual covered emergency procedures, risk management strategies and administrative matters.

During the second half of 2006, UCCO decided to terminate the development phase of the project and negotiated together with the families a live version of the service model. This approach makes available family governed funding as well as individualised funding for people without family support and who are able to manage their own care arrangements. The new arrangement is flexible and makes available a wide variety of care and support modalities. Consumer participation occurs by means of a newly formed Individualised Funding Advisory Group. All families were invited to participate in this new forum and around one-third took up this offer. UCCO is systematically reviewing and re-designing the programmatic safeguards that help consumers to remain safe, healthy, and in control of their financial commitments. A detailed account of this CDC model is beyond the scope of this article and will be published elsewhere.

Discussion

Participatory methodologies have become the tools of choice for government as well as national and international NGOs providing services for people with disabilities (Bruyère 1993; Kosciulek 2000; Burns 2007). They have been included in a range of implementation guides and manuals have been developed that seek to facilitate the inclusion and involvement of people with a disability and their carers in programmes such as CDC (Turnbull and Turnbull 1991; Braye 2000; Kemshall and Littlechild 2000; Simon-Rusinowitz et al. 2000; Mahoney et al. 2002; Lord and Hutchinson 2003; Phillips et al. 2003; Phillips and Schneider 2004; White et al. 2004; Simon-Rusinowitz et al. 2005). However, few of these publications explore how consumers can be systematically involved in the lengthy policy- and decision-making processes underpinning the development of programmes for people with disabilities. Moreover, within the wider participation literature, few studies systematically evaluate participatory approaches. In this article we attempt to fill this gap by describing and evaluating a PAR-inspired methodology that engaged consumers over several years in a project design process.

Most of the issues that came to the fore in the above case study have their origin in methodological deficiencies of the PAR approach that underpinned the project development. Whereas PAR-inspired methodologies are ideally suited to bring together in negotiation key stakeholder groups, participation is far from a given. Indeed, PAR is rooted in a vision of a romanticised ideal community in which people come together in the pursuit of the common good, get along, work collectively towards a collectively agreed upon goal and transform society in the process. However, more often than not, the reality is rather different. Incompatible personalities, differing opinions and world views, as well as competing interests undermine collective endeavours. And the time participants are willing to contribute to the research venture competes with other, at times, more pressing priorities. In other words, to foster and sustain participation over extended periods of time can be hard work. And community development can become one of the core activities action researchers find themselves embroiled in. However, the fostering of participation may require substantial resources that are usually not budgeted for. It involves the planning of project phases that were not anticipated and/or have rubbery timelines, the management of project components whose participant numbers are fluctuating, and succession planning for highly specialised roles that are difficult to replace and for which there may be no funding. The elements that turned out to be of crucial importance in UCCO's PAR-inspired approach were community development, ongoing group support, capacity building, as well as succession planning and project management.

While the international literature tends to feature examples of collectively governed projects that require little in terms of community building input (Kendrick 2001), this was clearly not the case in the above example where families worked together primarily because they were led together by a skilled project officer. Although officially employed to other ends, it was the ability of the project officer to bridge differences of opinion, bring together people with competing agendas, and to mediate personality clashes facilitating considerable consumer engagement during the first 2 years. The loss of this 'community builder' was disastrous for the project as it effectively allowed interpersonal differences to come to the fore and dominate collective processes. This undermined the action research infrastructure and essentially ended the collective governance process. Hence,

> PAR approaches for policy or project design have to include dedicated resources for community building.

The above case study also demonstrates that the development of participatory relationships required much effort beyond the initial start-up phase. To be sure, collective governance programmes demand a great deal in terms of ongoing commitment from consumers and flagging consumer enthusiasm is likely to occur especially after the novelty of programme has worn off. The reality of the step by step negotiation process that inevitably follows the euphoria of becoming part of a new project is often experienced as tedious by participants. Hence,

> If consumer engagement is sought over extended periods of time or for labour intensive tasks, resources have to be set aside for group support activities.

Group support, for instance in the form of financial support, coaching, and admin assistance, is especially important during latter stages of the programme design process. In UCCO's above-featured CDC programme, group support was wavering due to programmatic but also due to operational constraints resulting in a fragmentation of participatory

structures during the latter stages. However, UCCO's experience also demonstrates that, if such resources are made available, consumer engagement can be rekindled even after prolonged periods of low participation levels.

Alongside resource constraints, one of the key obstacles encountered by the project leadership was that of succession planning. Because funding for the project officer was limited to 2 years and because project participants were unwilling to collectively finance the position, the project leadership found itself in a position where it was unable to give continuity to group support. When it eventually was in the position to allocate resources to the project, it found it difficult to find an experienced 'community builder' with the right skill set. In fact, it became apparent that the previous project officer had grown into the role over time. Three years into the project, the leadership was faced with the problem that expectations of participants and staff towards a possible replacement were substantially higher making it difficult to find a suitable candidate. Moreover, subsequent staff members entrusted with the role found it hard to pick up the project without coaching and a handover period. In other words,

> *A succession strategy supported by adequate resources is essential for project continuity and sustained participation.*

Capacity building proved to be an enormously important factor contributing to the overall outcome of the project as it provided the knowledge basis that allowed project participants to make informed decisions. Participants were given the opportunity to attend seminars, capacity and leadership-building workshops, and were able to meet with participants of already established CDC programmes. Moreover, during the first 2 years, participants had access to easily digestible information compiled by the project officer. Over time, however, as resources became scarce capacity building initiatives faded into the background. Subsequent project officers regarded capacity building as secondary largely on the bases that because participants had acquired an advanced level of expertise they no longer required training. However, over time, the underpinning assumptions of the project, its institutional context, as well as many of its key processes changed significantly. New evidence that could have been used during the re-development of the project became available but was not disseminated. Moreover, project participants were entrusted with new tasks, such as the negotiation of industrial relations agreements, for which they were ill-prepared. Indeed, the above case study suggests that

> *In order to make informed decisions, participants require capacity building even during latter stages of the project.*

Consumer participation does not automatically lead to the development of policies and/ or procedures that reflect risk to consumers or service providers (see also Moseley 2001). When used for policy or project design in health and/or social care, a viable risk management strategy has to be identified and implemented.

> *PAR approaches for policy or project design have to address the potential risk to service recipients, service providers, as well as governmental agencies.*

Whether to involve consumers in the development process of such a strategy and to what degree has to be determined. Consumer consultations collecting value or preference statements in response to pre-designed policy options may be more viable than the development of a risk management strategy using a PAR framework.

However, if the risk management strategy is to be developed in a PAR fashion, the process could be broken down into iterative **operational** as well as a **methodological** 'reflection rounds'. A central feature of the operational reflection round could be a detailed risk assessment process focusing on:

– The potential financial, legal, health, and safety risk of the proposed outcomes to consumers; and
– The potential financial, operational, and legal risk to the agency

Furthermore, the operational reflection could include a careful feasibility assessment that takes into account the likely operational, financial, and managerial requirements of the proposed policy/programme. This would help to determine whether the consumer-generated proposal is adequately balancing consumer choice, safety, and agency responsibility and whether it is financially/operationally feasible. The findings of each operational reflection can then be fed into a deliberation and negotiation round that involves all stakeholders. The outcome of each operational reflection has potentially important ramifications for the methodological reflection as it will help to determine the management, support, and knowledge infrastructure that is required for the next PAR iteration. Also, the methodological reflection process can bring into focus the key issues that are to be negotiated during the following PAR iteration. Again the outcome of the methodology reflection process can be fed back to project participants and form the basis of a deliberative decision-making process determining the agenda of the next iteration.

However, this ideal scenario is only viable if consumers are highly motivated <u>and</u> have the necessary time at their disposal to engage in such a relatively time-consuming process (see also Ottmann and Street 2007).

Table 2 summarises the key lessons that can be drawn from the above case study.

Table 2 Five lessons for a PAR-inspired an approach for policy and project design

Lessons learnt	Implication for practise
Effective user participation should not be regarded as a given and may require substantial input	Expenses for community development should be routinely included in the budget. The drafting of community development strategies may provide useful guidance during implementation
Consumer engagement is often flagging when the initial euphoria of participating in a new and exciting project gives way to the step by step negotiation process that follow it	Low engagement periods are to be expected in PAR projects that cover extended periods. The projected workload for participants has to reflect this. Additional resources have to be budgeted for financial and admin support, coaching, and fun activities
A succession strategy supported by adequate resources is essential for project continuity and sustained participation	A succession plan for key project staff that allows for significant overlap and handover has to be in place and budgeted for
In order to make informed decisions, participants require capacity building even during latter stages of the project	Capacity building activities should be designed and implemented throughout the life of the project
User participation does not automatically generate policy outcomes that reflect risk to users and service providers	Decisions regarding the development of a risk management strategy are fundamental and have to precede the PAR process

Conclusion

This article critically reviews and evaluates the PAR-inspired approach that underpins a community based consumer-directed disability care project. It identifies methodological limitations and, based on the lessons provided by this case study, makes recommendations geared towards the development of a PAR approach that is more suitable for deliberative policy and programme design within a health and social care context. PAR is ideally suited to bring together in negotiation various stakeholder groups. However, participation should not be regarded as a given nor does it automatically incorporate the kind of risk and safety considerations that are fundamental within health and social care contexts. Community development, group support, and capacity building as well as risk management and succession planning proved to be vital in this case study.

Although the rhetoric of user participation in the development, implementation, and evaluation of health and social services features widely across medical fields and social science disciplines, comparatively little has been written about how deliberative user participation can be effectively integrated at the policy and project design level without being scaled back to minimal, perfunctory user consultations. If consumers are to shape health and social care policies more widely in future, methodological tools have to be developed that are more in tune with the needs of policy makers. The article suggests that the use of a PAR-inspired methodology that is adapted to the policy context, can lead to flexible and responsive programme outcomes that benefit consumers.

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