

Being Heard

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Abstract

This paper reflects on the experience with two very different projects designed to amplify community voices in relation to health service design. Looking back it appears that both projects address two pairs of related questions.

- What makes it harder for some (age) groups to be heard by institutions in society? What makes it harder for some institutions to listen to particular (age) groups?
- What has ageing got to do with being heard? What has being heard got to do with ageing?

Key Words: community participation

1. **Institutions trying to listen**

Many of the significant and influential institutions in society have policies in place which claim to recognize the service and political benefits that arise from building some form of community participation into their governance, decision making and marketing strategies. These participatory structures range from being comprehensive and genuine, to processes which are superficial and tokenistic.

In most societies the trend in terms of such efforts and commitments to involve the community is towards greater degrees of involvement. Gaventa and others speak of a movement to deepen democracy. Public expectations about having a greater say are also increasingly widespread. The resources, effort and imagination invested in attempts to create spaces and processes where people can speak out and speak together varies widely from project to project, and from agency to agency.

It is also the case that some age groups are listened to more than others. This is an important dimension to the process since the degree of recognition extended to different age groups in society by state and other formal institutions has an impact on the individual's experience of that life stage. Why do some groups (including age groups) experience more problems than others when it comes to being heard by institutions and organisations?

2. **The two projects**

This paper reflects on some of the lessons learned from two quite different and imaginative participatory projects involving a health service. One worked with older women and the other with high school students. Both sought to influence and change the way that health services are conceived, designed and delivered.

Over the last few years in Australia many summits have been held at national, state and local levels. These public forums have attempted to address a range of issues. The *Youth Health Summit* was as an attempt to identify the health issues of concern for young people in the northern Sydney area. The summit took place in April 2008. Eighty-nine high school students attended. The summit utilised technologies such as electronic keypads for immediate feedback and youth culture tropes like theatre sports to engage participants and reduce the distinction between the health service, its staff and the participants. applied anthropology

The research part of *Kicking Up Autumn Leaves* took place in 2005, with the report launch taking place mid-2006. Representatives of the Older Women's Network (OWN) Wellness Groups approached the health promotion service with a request to assist them with the evaluation of their project. They were most emphatic that this evaluation be conducted in a manner that was congruent with their wellness philosophy. The evaluation was designed to both broaden and deepen our understanding of wellness in older women and to design and conduct the evaluation in ways that enabled meaningful participation in the research process by the older women involved. How the story harvesting was done was as important as what we discovered. (KUAL – summary)

One thing common to both these projects is that they were optional for the agency involved. The workers and the services didn't have to undertake them. They were initiated by workers committed to the cause of community participation. So issues of reluctance, passive and overt hostility, sabotage, tokenism which often create problems for community participation projects were not a feature of the relationship between the agency and its community constituents. Nevertheless things did not always go smoothly.

Both projects attempted, in very different ways to turn the tables on the experts; to subvert the normal power relationship between community members and professional experts. Community expertise was as far as possible given a similar value as professional expertise. In many ways we were attempting to create a saturnalia effect [where in ancient Rome masters and slaves switched places once a year]. The strategies for achieving this can be superficial using artwork, music, décor and location. On the other hand deep attempts at creating such an effect are based in a genuine appreciation of

the other people and as a consequence giving them the same entitlements to analyse, edit and veto the output of the process.

3. Interpersonal dynamics

The interactions between the agents of formal institutions and members of the community are neither simple nor binary. At one level there appears to be a cycle where institutional actors and agents influence the life experience of community members with their imperfect efforts to listen. At the same time, community groups and individuals as they interact with public services across their life course influence the strategies selected by institutions and agencies. The ways in which people are expected, allowed and encouraged to participate in the governance of public agencies is an influence on individual and group identity formation.

What are professionals recognizing when they designate a group as being 'hard to reach'? There is a research and practice literature about attempts to engage the hard to reach populations of our society. Less frequently is the problem framed in terms of deficiencies in our outreach strategies. This tendency to locate the problem in the marginal population is part of a long tradition of victim blaming.

Hard to reach age groups are often those whose values least resemble those of the institutions that are trying to reach them. Sometimes this just boils down to being different from those who work for the institution. Those who appear to deliberately reject the codes of the institutions tend to be more harshly judged. Perhaps because their display is felt by the agents of the institution as a rejection of the value choices they have made in choosing to work for that particular organisation. Even in the health system where there is a clinical appreciation of 'hard to reach' conditions such as Alzheimer's disease, autism, Asberger's syndrome, such tolerance doesn't always spill over into daily practices in communicating with people who are socially or culturally hard to reach.

The central requirement of bureaucracies for documentation, usually in a preconceived form, leads to a privileging of the literate client and client group. Fluency in the dominant language or jargon of the institution is appreciated by workers as long as they don't end up feeling threatened by the fluency of community members whose expertise is not supposed to intrude on, or exceed the institutional literacy of the professional expert.

More broadly there is a social literacy or performative capacity of knowing the 'rules of the game'. Those who have difficulty with any or many of these literacies become the 'hard to reach'. These expectations about institutional literacy make it harder for young people who do not have extensive experience with the major institutions of society. It is not a social skill that is taught in schools, and in the case of health, if you live a healthy life you will not accumulate sufficient fluency in the institution's norms and

mores. It falls to the disabled and aged to develop a high level of literacy about the health system from their more frequent interactions with it.

This is one of the dimensions where the two projects diverged significantly. The older women had a lifetime of experience of the formal and conventional health system. This experience had inspired them to create a totally different pathway to wellness. They were quite suspicious of us as agents of the public health system and took some convincing that we could deliver something different from what they had experienced from other health professionals in the past. Some way into the project, they acknowledged that they routinely caucused outside the meetings with us to make sure that we did not deviate from the contract that we had struck with them. As some point the trust was sufficient that the caucus meetings ceased.

Opportunities to participate in the governance of institutions that provide goods and services are not equitably distributed in the community. Opportunities to contribute views and opinions do not simply increase with age, though as noted earlier the older health consumer can have an advantage of experience. On the other hand we often encountered stories where one of the dysfunctional elements was default deference that a proportion of our older women felt towards doctors, having been born before World War Two.

The degree to which conventional institutions are prepared to accommodate greater participation is potentially a major driver for change in how different age groups relate to each other. Participants often draw comparisons between how other groups are serviced and themselves. These comparisons most frequently highlight a perception that they are being neglected. There are many such entry points of disappointment in the relationships that people have with ostensibly caring institutions; points in the care process where the community feels let down, disappointed and betrayed by the institution.

Where groups that are organised around age, such as OWN make an effort and commitment to organise and design their interactions with formal institutions such as universities and health services then they are better able to move the agency and its workers to their way of seeing things. In the case of OWN and their Wellness program we are talking about an effective and well developed program of many years standing. This gave the participants a legitimacy and confidence which was not available to the young people at the *Youth Health Summit*.

3. The place of storytelling

In very different ways both projects provided a safe and stimulating place for the telling of stories and truths which are not usually expressed. Creating and holding spaces where marginalised stories can be told, heard and honoured is a central skill (Pinn). In creating such a space we need to start by acknowledging that the hegemony of the institutional, bureaucratic,

scientific, instrumental discourse over local story telling modalities is pervasive, but not all-pervasive. Thus we start by designing the space and creating rituals that subvert this hegemony in a way that is deliberate but not obtrusive. We create celebrations, liminal moments and relationships where the dominant rules and roles of knowledge creation are reversed.

Indicators of successful story telling spaces and processes manifest in some quite obvious ways. Did the participants stay awake? Did they get carried away by the process with the result that they were willing to put more into the process than they had originally agreed to? Was there laughter & tears? poetry & pictures? spontaneity & improvisation? In many ways the sort of events we are talking about are the antithesis of bureaucratic information gathering praxis.

The treasuring of stories harvested is a key feature in the process and one where a previously user-friendly process can flip into a sterile academic, bureaucratic process. Saying at the end of the story harvesting that we will take their material away and write it up and send it back for comment is quite fraught moment. Being given someone's story to carry and nurture is not a casual transaction. There is a lot of implicit trust. In the *Kicking Up Autumn Leaves* project, involving the crew of older women in the analysis was very important and it emerged as the process unfolded rather than being part of the original research design. Once stories, themes and conclusions had been clarified and agreed upon by the group, the write-up was conducted by one person.

The honouring of stories as a rounded wholistic way of theorising life narratives struggles against the efficiency of linear, instrumental theorising. Such instrumental reasoning has been foundational in creating the major service bureaucracies in modern societies. Policy formation, particularly in an environment of severe resource constraint, does not lend itself readily to the messy and discursive stories which people keep wanting to tell us. In the *Kicking Up Autumn Leaves* project we attempted to accommodate such instrumental reasoning on the basis that it might have tactical advantages in communicating with funding bodies. We attempted to use the SF-36 quality of life questionnaire to give us quantifiable comparisons to indicate the impact of the programme. However due to the short duration of the evaluation period, all we could legitimately compare were the different participant groups.

How we listen to what people have to say to each other is fundamentally important and a crucial feature of this process that does not often get considered is gratitude. Without the input of community experts the whole participatory project is going nowhere. Usually institutions gather community expertise at no cost, or at most, a minimal cost. Acknowledgement of this contribution, when it occurs, comes in a range of forms. From an instrumental perspective workers in many institutions

recognise the practical benefit to the organisation. The more we know about what people think about our services, the easier it becomes to design services which are effective. From a more appreciative perspective we can acknowledge the intrinsic humanity and spirit of the speakers. Increasingly there are policies which stipulate that community participation will be part of the governance process of the organisation and in such contexts the acknowledgement can be motivated by cynical instrumental considerations as the presence of a community expert enables managers to 'tick the box'.

As health workers our focus was biased but this was always explicit, and this may have influenced the stories that emerged which tended to be about people navigating the emotional geographies of the health system. Our participants, old and young, were mindful of the painful irony that there was clear evidence that the health system is partial in the care it extends to the communities it claims to serve. Another theme in the stories was about what health and wellness means for them in a daily sense when they are not engaging with the health system as a client. They told us stories about what they do to maintain their health and wellness and they were quite mindful of how this did not correspond with what the conventional health system would recommend.

4. Imagination

In reaching out to the hard to reach, or those we take for granted, we need use our imaginations and approach the exercise as true voyage of discovery rather than a confirmation of a hypothesis or preconception. Different institutions have different thresholds of tolerance when it comes to accommodating and funding, imagination and creativity. This spills over into discussions of what is possible and to what extent the community might be listened to. The outcomes of these discussions tend to be recorded in terms of reference or project objectives.

Meaningful involvement in problem solving and service design is often a process that is fudged and contested. The degree to which involvement is meaningful also changes with time and past experiences of the participants and stakeholders.

There appear to be different assumptions about whether some age groups require imaginative approaches to story harvesting. Creativity in the young is more highly privileged than in older groups. Both projects show that imaginative approaches can be rewarded regardless of the age of the participants. The form that the imagination takes in practice will differ significantly, and this is entirely appropriate.

5. Conclusion

Groups are marginalised for many reasons and age does not always feature as a significant dimension. In terms of groups wishing to have a say

in the health system, there is an asymmetry of power which is age related. This could in part be motivated by the self interest of workers in the health system, many of whom are baby boomers who are quite emphatic that they expect the health system to listen to them in a way that was not the case for their parents.

On the other hand there are many similarities between the projects. The use of story telling in the vernacular of the age group is one common feature, as is the fact that both groups were responsive to a sensitively applied imagination.

There will always be a struggle amongst stories for supremacy, and the playing field is seldom level. To translate the issue into health language, whose diagnosis prevails is not a marginal question. The public health system in contemporary societies is set up in such a way that favours the stories of conventional medicine. Defenders of this status quo would point out that this is the only safe position from which to prosecute the discourse. Other voices would contend that such a perspective prevails at the price of excluding large and significant parts of their health experience.

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