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Community participation for rural health: a review of challenges

Amanda Kenny PhD,* Jane Farmer PhD,* Virginia Dickson-Swift PhD† and Nerida Hyett MHSc‡

*Professor, †Senior Lecturer, ‡PhD Student, La Trobe Rural Health School, La Trobe University, Bendigo, Vic., Australia

Correspondence
Amanda Kenny PhD
Professor
La Trobe Rural Health School
La Trobe University
Vic.
PO Box 199
Bendigo
Victoria 3550
Australia
E-mail: a.kenny@latrobe.edu.au

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Abstract

Context Internationally, community participation is highlighted in health policy reform as good for rural communities. Implicit in this policy is the message that the complexities of the rural environment are too difficult for easy solutions and that community participation will somehow build resilient, self-determining communities capable of dealing with complex rural access and equity issues and poorer health outcomes. The underpinning proposition is that by giving decision-making powers to community members, health care will be locally responsive, costs will be contained, and health outcomes will improve. What happens in the practice of enacting community participation in health-care decision making is less clear.

Objective Despite the growing body of work that documents different levels and models of community participation, significant gaps that outline the practical challenges inherent in rural community participation remain. In this article, we draw on a body of literature to outline the practical considerations in implementing community participation policy in health settings in rural areas. Through a critical review, we aim to stimulate debate, progress ideas and provide a conceptual representation of the somewhat 'messy' nature of rural community participation at a grass-roots organizational level.

Discussion and conclusion Based on our analysis of the current literature, we provide a summary of challenges and practical strategies that might mitigate some of these challenges. Our review highlights that despite policymakers suggesting that community participation is good for rural communities, policy enactment must move beyond mandated tokenism for there to be a recognition that meaningful participation is neither easy nor linear.

Introduction

Community participation in health-care design and coproduction is increasingly highlighted in health policy reform in the United States,[1] Canada,[2] Asia,[3] Europe[4] and Australia[5] as good for rural communities. Implicit in this policy is a view that rural settings require

customized solutions[2,4,6–8] and that rural communities are appropriate places of participation. There is an assumption that involving citizens will build the resilient, self-determining communities needed to deal with complex rural issues of access, ageing, and poor health and social outcomes.[9]

Coproduction is a term increasingly evident in key policy documents when referring to participation and is defined as a collaborative approach to bringing together professionals, people using services and citizens to develop and deliver public services.[10] The underpinning proposition is that by giving decision-making powers to community members, health care will be locally responsive, costs will be contained, health outcomes will improve, and health professionals and health systems will be more accountable.[1,2,8,11]

Whilst governments across many developed countries are promoting community participation as central to health reform,[8,12–15] a major policy flaw in the current community participation agenda is acknowledgement by governments, sometimes quite overtly, that they are unclear about how meaningful community participation will actually be achieved.[11,14,16] Increasingly, there is a move from governments in several countries to mandate community participation by linking it to quality and safety reporting.[17–19]

As researchers, we work closely with rural health service partners who struggle to enact mandated standards that require communities to participate at all stages of health-care design, delivery and evaluation. Whilst we are located in Australia, it is evident that there is a lack of international knowledge on the enactment of community participation at a grassroots level. This impedes the ability of rural health services to identify what meaningful community participation might mean for their organization, their staff and the communities that they work with.

In a previous review (add reference to our 2013 article following peer review of this manuscript), we sought to identify examples of community participation in rural health care that could support participation processes at a community level. We found few examples, and those that did exist lacked critical analysis of the rationale for rural community participation in health care and the challenges that communities face in enacting participation policy at a local level. There was little discussion of processes, inclusion or health/social outcomes. Our findings were consistent with other researchers who argue that there is limited evidence of outcomes from community participation across all health-care settings, not only rural.[20,21] Our review revealed a gap in knowledge of the practical challenges inherent in rural community participation, and it is this gap that we seek to address here.

Method

Our research question for this study 'what is known about the practical challenges in enacting rural community participation' informed our choice of review method. Grant and Booth[22] provide a useful typology of reviews, and from their work, a critical review aligned best with our question and purpose. Critical reviews are used to source, analyse, synthesize and 'take stock' of a diverse range of literature.[23] The focus is on the conceptual contribution of a broad range of literature, rather than an assessment of the quality of the work.[22]

Whilst typically critical reviews do not include formal presentation of search strategies,[22] we believed that a documented search was useful to meet our aim of identifying and providing commentary on the challenges of rural community participation. We identified key search terms reflecting our research question, and the following Boolean search string was used: (rural or regional) AND (population or health care or community) AND (communit* or consumer or citizen) AND (participation or engage* or collaborat* or partner*). The use of truncated words and wild cards (*) enabled a broadening of the search to capture terms with the same root. The search was conducted in Medline, CINAHL, Proquest, Expanded Academic and Informit.

Our initial search yielded 2467 articles. Following a scan of titles and abstracts, large numbers were excluded, as most were focused on patient consultation. We focused our study on developed countries, and after excluding literature from developing countries, 99 full-text articles were retrieved. We then hand searched reference lists to capture key additional literature on community participation. Through a process of in-depth reading, we extracted information about challenges in community participation and aggregated these challenges under three main clustered headings: shared understanding, governance and practical application, and sustainability. Consistent with limitations of critical reviews, our 'interpretative elements are necessarily subjective',[22] but we did achieve agreement through a team approach of discussing sourced literature, clustering and cowriting.

In presenting our review, we aim to illuminate challenges in the practical enactment of health policy. Our purpose in doing this is to stimulate critical debate, progress ideas and provide a conceptual representation of rural community participation at a grass-roots organizational level.

Shared understanding

Definitional challenges

'Community' and 'participation' are debated terms,[24–28] which create challenges for those seeking to start local initiatives. Participation has been variously defined in terms of individual, personalized relationships, through broad collective citizen involvement,[17] 'meaningful' engagement,[5] active involvement in policy implementation,[18] shared or delegated power,[29] and coproduction.[30]

Common definitions of 'community' include people in a relatively bounded geographical area,[31] a social space with interactions and transactions,[32,33] people with social and cultural affiliations and common norms and customs,[28] and people who drive locally beneficial solutions.[34] There is a premise of a somewhat cohesive group of individuals with a common purpose and shared focus.

However, whilst rural communities are sometimes characterized as bound by relationship ties and unofficially governed by local hegemonies,[35] classically portrayed in the notion of *gemeinschaft,*[36] the need to be cognizant of the complexity and changing nature of rural communities is an important consideration prior to embarking on community participation initiatives. Assuming that communities will welcome participation opportunities and engage as 'well-behaved' citizens is at best naïve. Oakley's[37] (p. 4) comments about rural people, whilst almost two decades old, are a timely reminder of rural complexities:

> Participation...cannot merely be proclaimed or wished upon rural people... It must begin by recognising the powerful, multi-dimensional and, in many instances, anti-participatory forces which dominate the lives of rural people. Centuries of domination and subservience will not disappear overnight just because we have 'discovered' the concept of participation.

Community participation: purpose and rationale

When embarking on community participation at a local level, having a clear understanding of its purpose and rationale would seem a basic starting point. However, globally, there is debate on motivations for policy's emphasis on community participation.[27,38] Questions are asked as to why greater community participation is espoused in countries with the democratic right and power to influence political decision making, through free and open electoral voting processes.[27,39] Normative arguments centre on active citizenship, as key to quality democracy. The focus is on cohesive social capital and good governance, including scrutiny of governments, to increase transparency, honesty and accountability.[27,39] Instrumental arguments[27,38] centre on service users having valuable insights into service delivery and improvement, ensuring service efficiency and effectiveness.[40] In complex and controversial situations, it is argued that diverse groups of stakeholders may assist in reducing conflicts, by harnessing collective problem-solving to

address 'wicked' or complex problems that require collective input.[41]

Critical questions are posed as to whether community participation is simply governments' attempts for legitimization[39] or neoliberal underpinnings of passing responsibility for design and delivery of services to end-users.[39,42] It is argued[27,38,43] that democratic governments have been traditionally reticent to delegate any real power in decision making, beyond the political gain that might be engendered through being seen to listen to the 'voice' of the people. Whilst these debates centre largely on participation at a macro level, they do provide a cautionary note at the rural community level. Questions could be asked about the purpose, goals and focus of a community's participation and whether there are local organizational commitments to delegate decision-making power, or whether participation is designed simply to meet statutory requirements (i.e. bureaucratic box-ticking).

Embedding community participation in a meaningful way means to move from 'symbolic' or 'representative' engagement to direct, cogovernance, involving communities in the planning, design and delivery of health and well-being services and amenities.[42,44] When participation is embedded at operational levels, it is expected to define and uncover solutions to complex local problems, create momentum and draw on expertise from diverse sources of knowledge, including practical experiences of those working and living in the proximate field.[27]

Whilst the concept of participation emerged through international health policy,[45] a range of interpretations of community participation and foci of its application have developed, and we argue that confusion has resulted, to an extent impeding more widespread adoption in the rural context. The WHO[46] interchangeably refers to 'participation' 'involvement', 'engagement' and 'empowerment', and this creates widespread confusion.

In rural policy,[2–5] community participation is suggested to be good for rural communities without much explanation of what it means. As Morgan[24 (p. 222)] explains,

> The proliferation of meanings attached to the phrase 'community participation in health'... has allowed it to be analysed as a political symbol capable of being simultaneously employed by a variety of actors to advance conflicting goals, precisely because it means different things to different people.

Regarding rural places, variation in understanding might be expected due to heterogeneity of rural contexts, nationally and internationally, and the consequent mix of demographics and pertaining policy frameworks. Indeed, participation has been described as an umbrella term, suggesting an on-going, active relationship with shared power and ownership, understood in different ways by different people.[15]

Lack of shared agreement on theoretical frameworks

Theoretical models or frameworks to underpin community participation are debated. Since 1969, Arnstein's ladder of citizen participation (Fig. 1) has been promoted as the seminal community participation model. It represents the redistribution of power from 'government to the governed'.[29]

However, since the 1990s, critics of Arnstein[26,47–53] have identified issues with the ladder, including lack of consideration given to the quality of the participation and limitations associated with the categories chosen. Modifications, refinements and adaptations of Arnstein's ladder have occurred with those by Burns[47] and Wilcox[49] most commonly cited.

Despite these refinements, contemporary authors[50–53] critically reject the use of Arnstein as the 'touchstone for policymakers and practitioners'.[53] It is argued that refinements to the model have promulgated hierarchical thinking, with uncritical embracing of power as a single dimensional, finite commodity that can be seized by citizens and used to shape health decision making.[50–53] Bishop and Davis[50] argue that the simplistic, linear notion of participation

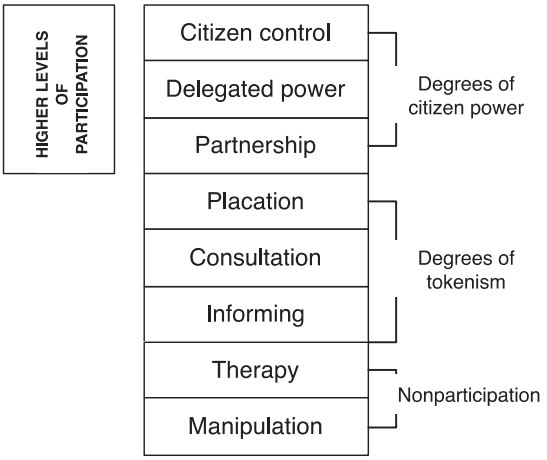

Figure 1 Levels of participation. Adapted from Arnstein S. A ladder of citizen participation. Journal of the American Institute of Planners 1969, 35:216–224.

creates a false view that policy problems are static and that different levels and types of participation are needed to address the same problem.

Critics contend that Arnstein's top rung, citizen control, creates a view that any participation below this level is not legitimate[51] and fails to acknowledge that for different people and different purposes, different levels may reflect successful participation.[52] Tritter and McCallum[53] refer to 'dangerous snakes' in Arnstein's ladder. Using the analogy of snakes, they describe a multitude of issues that limit participation and argue that the ladder is built on the 'assumption that power will trickle down from involvement'.

Focusing on groups that may be disadvantaged, Tritter and McCallum[53] and others,[50,51] argue that the emphasis on citizen control has a risk of capturing popular opinion without attention to involving disadvantaged citizens. Others[52–54] contend that hierarchical models assume that all people want to be involved in the same way, rather than capturing the desired level or type of involvement of different community members.

In arguing that the transfer of power to citizens has the potential risk of creating adversarial positions between policymakers, service providers and users (and indeed within these groupings), Tritter and McCallum[53] propose that community participation is more like a 'vague mosaic' than a ladder with defined rungs. Collins and Ison[52] argue that the fundamental flaw in Arnstein's and adapted models is the lack of consideration of how all stakeholders might work together collectively to pursue an issue that is contested or ill-defined. Their proposition is social learning, which they define as learning that occurs through situated and collective involvement with others. They argue that this is more appropriate to reflect interdependencies, complexity, uncertainty and controversy. Whilst they argue for a new policy paradigm of social learning for concerted action,[52] they also acknowledge that lack of a consistent theoretical underpinning for community participation is a challenge for those wanting to embrace different approaches.

The lack of evidence for embracing participation

Health-care providers' interest in community participation may be provoked by the argument that community participation is useful to manage health-care rationing and decentralization, and thus central to efficiency models that are localized to regions and community priorities.[55,56] However, researchers argue there is little evidence of widespread policy change to locally appropriate, diversified, health-care delivery models as a direct result of citizen inputs to design.[57]

In a number of case studies, participation has resulted in improved infrastructure, funding and beneficial changes to service provision, and there is some evidence to suggest that participatory processes increase social capital and cohesion.[58,59] However, there are still gaps in evidence linking participation and health-care service improvements, particularly in the rural context. Study findings are limited in capacity to replicate or generalize, and scalability of small rural projects to larger systems and policy is unknown. There is a paucity of longitudinal research to demonstrate whether short-term efforts are sustained, or whether they result in

cost-effective solutions for rural health improvement objectives, such as reducing the burden of chronic disease and health spending.

When discussing rural community participation, Kilpatrick[60] states that engaging communities in health care is expected to have desirable outcomes for citizens, however, implementation has superseded robust research evidence and more needs to be known about whether participatory methods achieve anticipated results. More broadly, several authors have identified a paucity of research that identifies whether the outcomes of participation meet purported objectives.[14,38,61–64] This gap in knowledge presents a significant challenge when convincing all to participate.

Governance and practical application

Improving how government and related organizations work with communities is an international policy interest.[54,65–67] Researchers argue that the major challenge in rural areas is unequal positions of power, stemming from differences in social class, knowledge and expertise, societal position, and other educational and occupational advantages.[9] Williamson and Fung[68] describe information gulfs that separate different groups in the community, and knowledge that separates 'outsiders' from locals. In the rural context, Kilpatrick[60] argues that strong governance to bridge gaps is a necessary preparatory step for meaningful community participation.

However, evidence of governance models to support community participation is limited, particularly in the rural context. Ethnographic fieldwork in rural Australian communities in three states suggests 'governance is not a single process in which communities are, or are not, adequately engaged ... governance is comprised of different processes, instigated by different actors for different reasons, both in and out of dialogue with public agencies'.[54 (p. 55)] An important consideration is a pervasive view in many rural communities that those from government are outsiders with little understanding of how local communities actually work.[54]

Inclusion and representation are challenges in establishing governance, and in rural communities, this may mean an inner circle of key community leaders to developing an effective governance environment. As Morgan[24] highlights, the challenge is to develop governance frameworks that enable participation to arise from inside and occur as spontaneous and self-generating, rather than from outside or above. There are a few examples of governance structures that have partnered community members, health care and other service stakeholders to bring together lay and expert knowledge and community resources,[69,70] but the paucity of evidence-based governance processes provides a major challenge for local implementation.

Additionally, even in situations where governance mechanisms are established, government regulations, for example, that require community organizations to acquire formal bureaucratic processes such as working with children checks, food handling and insurances, present challenges that conflict with ways rural communities have traditionally governed themselves. This can serve to de-legitimize the communities' own forms of self-organization.[54]

Considerations of who participates

Questions of who participates, who does not and whether it matters, are challenging for enacting rural community participation. In participatory activities, community members are generally assumed to share a vested interest in making their community a good place to live. In rural communities, this can mean appointing 'local champions' or the 'usual suspects' to attend structured meetings and provide opinions or feedback.[69,70] It is expected that community members, who either self-select or are appointed, are able to set aside their individual interests and develop a shared vision for beneficial community outcomes. Methods such as citizen juries, neighbourhood committees, community forums and community champions are built on this premise.[21,71]

However, who really represents 'the community' is debatable.[54,65] Community members

may have conflicting interests, and individual conflicts between community members may determine who volunteers to represent others. Representative participation is common in rural communities with consumer representatives on local boards, networks or action groups.[72] However, by only including those who are available, have the capacity to participate in a power-compromised social setting, or who self-elect, participation may exclude others with diverse perspectives. Mechanisms to engage the disadvantaged and marginalized remain elusive.[34] Whilst there are some examples of inclusion involving disadvantaged or marginalized people and subcultures,[73] there is limited evidence to suggest that participatory approaches alone, without specific strategies to target marginalized groups, result in an inclusive model of community participation.[34,60] Insider–outsider tensions are widely discussed in the literature.[65,74–76] Eversole[66] contends that it is impossible to adequately represent those who are not directly participating. However, she acknowledges the importance of what she terms 'translation agents' – those people who are comfortable in the circles of both the powerful and the powerless and who are able to facilitate transactions among groups.

Whose knowledge counts?

There is a need to consider that different forms of community knowledge exist and how to access forms of knowledge. Local community knowledge is grounded in context, which challenges those external to rural communities to accept local knowledge as a legitimate form of understanding as well as to find ways to gain access to this information base.[77] Eversole[77 (p. 34)] argues that dialogue is often complicated by 'the persisting assumption that experts are still holding the only real "knowledge"'.

In the context of the rural community, longstanding community members can dismiss the views of others who are not considered 'real locals' as they do not have familial roots within the community. Whilst residents may have lived in the community for extensive time periods, they are not viewed as having legitimate claims to knowledge about the community until they have lived there for decades.[15]

A criticism of rural community participation approaches, is that one group (often endogenous and usually the more powerful), tries to 'engage' the other group, using its own processes. This may include having workshops and/or meetings that are presented in a format and language that makes sense to one group but can alienate others.[61,78,79] Cornwall[67] criticizes these 'invited spaces', highlighting that no matter how participatory groups seek to be, they are 'still structured and owned by those who provide them' as compared to spaces that people create for themselves.

Sustainability

Researchers argue[53] that for some people, participation itself may be their goal, that is without the necessity for some punctuating endpoint or output. They suggest that the opportunity that participation offers to come together for social interaction can be highly valued. However, there can be on-going demands for people to participate in various activities in their communities, which can result in what has been termed 'participation fatigue'.[21,67,80] In rural areas with small populations, this can pose a barrier to participation. Community members who have been involved in participation processes have reported negative physical and psychological health consequences including exhaustion and stress.[81]

Issues of sustainability have recently been drawn into the community participation and rural health literature as a measure or indicator of progress,[82] but the issue is problematical. The increasing association of participation, sustainability and rural health services may derive from issues related to service closure and changing rural population demographics. There is a risk in using community participation processes as an outcome or performance measure reported to funding bodies. Desiring sustainable community participation, in this sense,

may be imposing an artificial, indeed unhelpful measure that is useful to outside bureaucrats and not to local citizens.[83] Reinvigoration for the sake of funding may occur, or superficial changes made to programmes to meet requirements, denouncing the idea of 'full citizen control' and acting as a reminder to communities of who essentially has the power. Using sustainability as an outcome measure of participation may impose an endpoint to an otherwise continuous process of engagement and cultural change.[24] By compartmentalizing participation as a 'project' or 'product', political ideals are imposed on what may occur as a spontaneous, naturally occurring process of change.

In tangible terms, researchers have argued that the scale of participation indicates sustainability. Morgan[24] states that 'in order for participation to be sustainable it must extend beyond the local (or project) level'. Enduring through disadvantage, or disasters, and continuing to function under strain are included in the rural health conceptualization of sustainability.[24] Sustainability as an outcome of community participation might be better viewed as improved community liveability and enrichment, strengthened social connections, and liveable physical space and natural and built resources.[84] Farmer, Prior and Taylor[85] suggest that these dimensions, or resources, can be measured as stocks of types of capital when indicating outcomes for communities, where improvement indicates growth and prosperity in addition to longevity.

Discussion, practical strategies and conclusions

In this paper, we have drawn together literature to highlight some key challenges for enacting rural community participation. We are not suggesting that the challenges we have identified represent an exhaustive set. Rather our purpose was to provide a thought-provoking overview. Some issues raised are widely applicable to non-rural settings, but we argue that the rural environment creates a complex context that community participation policy directives[1,2,15,86] fail to acknowledge. Rural communities have small populations that must continue to live in proximity with each other, before, during and after participation exercises, and they tend to have ageing populations, which mean dwindling human capital. Whilst government acknowledges confusion over directions for enacting community participation, we argue that there are many issues beyond simply 'how to do' community participation. These make involving communities in health-care design and provision very complex for rural community health service providers.

Whilst the policy environment assumes that community participation is good for rural communities and many authors present arguments for community participation related to active citizenship, democracy, transparency, government scrutiny, collective problem-solving, social capital, and improved efficiency and effectiveness,[27,39–41] questions about purpose, goal and focus are fundamental and need, if not resolution, at least acknowledgement and discussion in policy arenas.

The proliferation of meanings of community participation,[24] definitional challenges,[24–28] and debate surrounding appropriate theoretical frameworks[26,47–53] provides a chaotic picture for citizens and health-care providers seeking clarity. Rural health services may be told that participation is central to local ownership and efficiency, but the paucity of evidence to support these contentions presents a significant challenge to convincing local stakeholders.

The intention of governance processes is to produce strategy and order, so the lack of knowledge of governance processes to support effective community participation[60] is a gap. In establishing community participation initiatives, there are complex questions of inclusion, representation, and legitimate types of knowledge. However, even if these issues can be dealt with, there is often tension between innovation and documentation of evidence on what works in the community participation space.

The challenge of enacting community participation and strategic imperatives of organizations results in questions of sustainability. There are risks associated with community

participation processes being viewed as outcomes or outputs, in that community fatigue from being involved in a multitude of projects, impacts on the ability to really harness sustained, long-term participation for change.

In drawing together the findings of our review, we provide a summary of the major challenges and propose some practical ways these might be addressed.

Shared understanding

Before embarking on community participation, it is important that all stakeholders have a shared understanding of the purpose and rationale. Organizations must be clear whether they are delegating real power in decision making or whether participation is simply meeting mandated requirements. Moving from 'symbolic' engagement to coproduction requires a commitment if shared ownership is to be developed. Early conversations between all involved are paramount. Importantly, organizations must clearly understand that participatory processes might not lead to solutions that fit with directions of the organization, locally responsive health care or improved health outcomes.

Bucolic, idealized views of rural communities might serve to perpetuate a picture of cohesive groups. However, these same views might serve to ensure that those who do not fit the idealized rural mould are further marginalized. There is a need for communities to have open and honest discussion about changing demographics and develop a number of strategies to engage with populations that are hard to reach. This might involve the use of peers to guide participation, participatory activities in different settings, the use of different participatory processes, including social media, and engaging in different, creative ways. There is a need to spend some time ascertaining the desired level or types of involvement of individuals and different groups.

Governance and practical application

Unequal positions of power are inherent in community participation. Consideration should be given to ensure citizens have practical training in participatory processes and where appropriate citizen advocates are engaged. Whilst inclusion and representation are challenging issues for governance, community 'champions' or key community leaders are useful to engage in planning and implementing a solid governance environment. The focus should be on developing strategies that support participation by marginalized population groups.

Sustainability

Participation fatigue can be a real issue in rural communities. Developing different ways for people to participate might be one strategy, but there is also a need to clearly recognize that all participation does not have to be protracted for a long time period to be sustainable. Sustainability as an outcome might be represented by improved liveability and strengthened social connection. The fundamental message is that organizations should be clear about what they are participating about, and once the issue has been explored and considered, it may be appropriate to cease participation on that issue.

In concluding, we argue that whilst policymakers may present community participation as a desirable process, where people queue in a somewhat orderly fashion, to climb the rungs of a ladder towards citizen control, the reality shows we are not at all sure about solid structures, organization and processes. Rural communities are not homogenous, connected and uniform. The analogy of a ladder suggests safety, careful steps and an upward climb. Our experience of community participation fits with Tritter and McCallum's[87] 'messy' description. Policy might suggest that community participation is good for rural communities, but if policy enactment is to move beyond mandated tokenism, there must be recognition that meaningful participation is neither easy nor linear. Critics of Arnstein refer to the snakes amongst the ladder rungs, but for rural communities, there is a need for fundamental awareness of the key challenges before even taking the first step.

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