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# *Independence and control in Indigenous community participation in health*

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**Abstract**

Over the past few decades, interest has grown in the decentralisation of governing across fields as diverse as education, health, and justice [1-3], enacted through a reduction in rigid hierarchical structures, increasing partnerships with civil society and localised decision-making processes—an impulse that has gone hand-in-hand with the rising discourse of community participation in health. Community participation in health is particularly relevant for Indigenous peoples, who are often excluded from decision-making and priority-setting in the development and implementation of health services. Indigenous community participation in health is not only a response to systemic barriers in accessing biomedical health care or a lack of culturally appropriate health care, but is underpinned by the principles of self-determination, autonomy, social justice and cultural retention.

Indigenous community participation in health in Chile has led to the development and implementation of a number of health services administered and governed by Indigenous community organisations. However, these decentralised governance structures, established to enable localised influence over policies, processes and services, are nevertheless contradictory in that they are strongly shaped by State power. This paper examines how staff from Chilean Indigenous community health care services perceive the concept and purpose of Indigenous community participation in relation to State policies and frameworks [4-6].

In examining the perceived role of Indigenous community participation in health, there were apparent tensions between the themes of community 'empowerment' and 'responsibilisation' [5,7]. Taken as a whole, interviews with staff from community controlled health centres highlighted a dual discourse around community participation and the relationship between community organisations and the State: interviewees spoke about the responsibilisation of Indigenous communities on the one hand—that is, devolution to communities of the responsibility for service provision and attendant risks that would otherwise lie with the State—and on the other, a desire

to increase Indigenous autonomy in health and more generally through the assumption of roles that allow for engagement and representation within the Chilean State. Corresponding processes are those by which the State shifts responsibility for service provision to communities and community organisations, but retains control of the ways service is provided through imposition of regulations and obligations, normally tied to financial arrangements [5]. Here, interviewees articulated the utilisation of participatory processes to increase Indigenous independence while at the same time being mindful of the necessity of compliance with such regulations imposed by the State in order to maintain this position.

The imposition of State-centred regulation onto Indigenous governance structures as a necessary part of the development of participatory models has profound implications for the capacity of Indigenous communities to realise their desire for independence and autonomy through these mechanisms. Consideration therefore needs to be given to how best to balance the ethical considerations such processes present.

**Introduction**

Over the past few decades, interest has grown in the decentralisation of governing across fields as diverse as education, health, and justice.[1-3] This has been enacted through a reduction in rigid hierarchical structures, increasing partnerships with civil society and localised decision-making processes—an impulse that has gone hand-in-hand with the rising discourse of community participation in health. Community participation in health is particularly relevant for Indigenous peoples, who are often excluded from decision-making and priority-setting in the development and implementation of health services. Indigenous community participation in health is not only a response to systemic barriers in accessing biomedical health care or a lack of culturally appropriate health care, but is underpinned by the principles of self-determination, autonomy, social justice and cultural retention.

The rights of Indigenous peoples to participate in health has been recognised by international legislation. The United Nations Declaration on the Rights of Indigenous Peoples (UN DRIP) obligates States to 'consult and cooperate…with the indigenous peoples concerned…before adopting and implementing legislative or administrative measures that may affect them'. The right to consultation is also tied to the right of Indigenous peoples to self-determination, also recognised by the UN DRIP.[9,10] Article 25 of the International Labour Organisation Convention (ILO) 169, the Indigenous and Tribal Peoples Convention, states that 'Governments shall ensure that adequate health services are made available to the peoples concerned, or shall provide them with resources to allow them to design and deliver such services under their own responsibility and control.' ILO 169 goes on to state that 'Health services shall, to the extent possible, be community-based. These services shall be planned and administered in co-operation with the

peoples concerned and take into account their economic, geographic, social and cultural conditions as well as their traditional preventive care, healing practices and medicines.'[9]

Decentralised governance structures, established to facilitate stronger community participation and enable localised influence over policies, processes and services, are nevertheless contradictory in that they are strongly shaped by State power. For example, State structures are central to the creation of spaces for community participation in health, and the way such spaces arise demonstrate the interplay between civil and State actors.[5,10] Financial arrangements of community governance structures form another axis along which community and State interactions are negotiated.

Drawing from the work of Foucault[4] and elaborated upon by numerous academics since,[5,6] governmentality explores the tensions between stated goals of increased democracy and community empowerment on the one hand and the ways patterns of power are reproduced and perpetuated through these structures on the other. Where community organisations seek State funding to pursue their own priorities, the imbalance of resources leads to community partners being tied to the agenda set by government, thereby limiting their capacity to initiate their own strategies. Furthermore, the burden of audit and compliance requirements that are tied to State allocation of resources may limit the time available for smaller organisations to do the work that particularly matters to them.[5]

Within Chile, Indigenous community participation in health has mainly been undertaken through the development and implementation of health services administered and governed by Indigenous Mapuche community organisations. Each of these health centres represents a unique model in providing biomedical and/or traditional Mapuche health services in negotiation with, and with varying levels of support from, State institutions, in particular the Health Service of South Araucanía (*Servicio de Salud Araucanía Sur*, SSAS), here referred to as the Health Department.[11]

Makewe Hospital is located within the Mapuche community of Makewe-Pelale, 25km south of Temuco, Chile. In 1998, an association of Mapuche leaders, the Makewe-Pelale Mapuche Health Association (la Asociación Mapuche para la Salud Makewe-Pelale), lobbied for and achieved control of the hospital, which had previously been established by the Anglican church. The Association consists of representatives from approximately 35 local communities, with a majority of members being Mapuche.[12] Health initiatives established by the Mapuche community have been based on the principles of self-determination and social, political and economic development.[12-14]

Makewe Hospital is contracted by the Chilean government to provide biomedical health services to the surrounding communities. The hospital had approximately 20,000 patients on file as of 2009, approximately 80% of whom are Mapuche,[13] and runs the following programs:

- Children's health program
- Adolescents' health program
- Women's program
- Adults' program
- Elders' program
- Oral health program
- Regime of Explicit Health Guarantees (El Plan de Acceso Universal a Garantías Explicitas en Salud , AUGE)[15]

While the hospital works closely with traditional Indigenous healers, the healers themselves do not work directly within the hospital and are not employed by the hospital. Instead, they are based within and supported through the community.[12] This reflects the philosophy of the Hospital that the two systems work best in a complementary fashion, with each being undertaken in its own space—the traditional system within the community, and the biomedical system within the Hospital.

This paper aims use the case of Makewe Hospital to explore how interaction with State structures upholds or undermines the realisation of Indigenous autonomy and self-sufficiency through community participation in health.

**Methods**

Twelve semi-structured interviews were undertaken with Makewe Hospital staff members between August 2015 and June 2016. Interviews were designed to allow for some consistency and comparison between participants while incorporating flexibility to explore particular issues important to the individual. The topics covered in the interview schedule were derived from literature regarding ambiguity and complexity in defining the elements of community participation; the role of participatory processes in determining and defining the health needs of a community; the influence of contextual factors and institutions on community participation in health; and the level of decision-making power communities have through the processes of participation.[16,17] The interview schedule was therefore designed to cover the following topics:

- The organisation and structure of participatory processes relating to Makewe Hospital
- Identification of local health needs
- The influence of participatory processes on responding to local health needs
- Factors that influence participatory processes

Recorded interviews were transcribed. Directive content analysis was used, as described in Hsieh and Shannon,[18] in order to code the data for content and themes. Coding categories were identified *a priori* (to explore key issues outlined above) and additional categories were developed to describe issues that emerged from the data. Directed content analysis was selected as the study aims to examine how the theory of community participation in health manifests within a particular context. This is in line with Hsieh and Shannon's indications that directed content analysis is appropriate when the goal of the analysis is to build or expand upon existing theory or research.

Ethics approval was granted by the University of Melbourne Human Ethics Subcommittee (Application number 1544845) on 20 July 2015.

**Results**

Interviewees saw the Makewe-Pelale Mapuche Health Association (the Association) as the pathway by which community interests and needs are represented within the Hospital as it fulfilled its basic duty to comply with the technical and service functions outlined in its contracts with the Health Department. In the course of undertaking these obligations, the Association was, at the same time, held up as a way of strengthening the standing of the Mapuche people in terms of political power more generally, as reflected in the following quote.

> *…I believe that the way the Mapuche people can move forward and have representation is through creating institutions that can decide within their territory and that's what the Mapuche Association is doing…. (Administrador)*

At the same time, the role that had been assumed by the Association in administering the Hospital was also seen as taking on responsibility that should rightly have been borne by the State—the provision of appropriate, accessible and adequate health care.

> *…the Association that we, that I represent is the one responsible for administering public health in Makewe territory, right? So we're doing what the government, the Chilean State should be doing as part of its own, its own responsibility, we assume that responsibility and we assume it so that in this territory the people can be cared for with respect, with dignity, with, with attentiveness, yeah? (Director of Makewe Hospital, President of the Association)*

However, there was recognition that engaging with the State in order to ensure participation and representation in the health system also necessitated being constrained by State requirements and policies. The following quote illustrates the utilisation of participatory processes to increase Mapuche independence while at the same time being mindful of the necessity of compliance with regulations imposed by the State in order to maintain this position.

> *… these institutions [such as the Mapuche Association] one has to strengthen them and in order to strengthen them indubitably as we're located within the Chilean State unfortunately, I repeat unfortunately, we have to adhere to their policies, their rules and their laws and all that, there's nothing else for it because if we don't adhere to these rules they'll regrettably say, "Right, this institution isn't following the rules and therefore it is outside of the system," and once we're outside the system we lose representativeness, we've lost our voice, we've lost in some way our development within the Chilean society. (Administrator)*

Interviewees spoke with varying degrees of frustration and resignation when describing the obstacles faced in working within State ordinances and regulations and attempting to navigate a system that was not designed for the reality of Mapuche needs either at the macro or micro level. One key way that the State was seen to curtail Mapuche community participation in health was through the number of institutional barriers to establishing Indigenous governance structures. Interviewees reported a lack of supportive legislation and highlighted the reliance of Makewe Hospital on DFL 36, Regulations to be applied in Health Department contracts (*Decreto con fuerza de ley 36, Normas que se aplicarán en los convenios que celebren los Servicios de Salud*)[20] as an example. DFL 36 was established in 1980 as part of the health care reform undertaken during the military dictatorship in Chile. Its purpose is to facilitate the privatisation of health care by allowing

State health care funding to pass to private entities. While the Association took advantage of this legislative 'loophole' to take over administration of the hospital, the law was not created with Indigenous organisations in mind and, in fact, there exist no legislative or policy structures that explicitly allow for Indigenous governance in health, which places the Hospital in a precarious situation.

State financing systems were created under the assumption that private health care providers would charge patients to offset the costs of providing care. At the same time, there is also funding set aside to address Indigenous health, for example through PROMAP in la Araucanía. Within Makewe Hospital's context, where a high proportion of patients live in poverty, it is not possible to charge users for services. However, neither does the Hospital receive funding allocated towards Mapuche health as they are funded as a biomedical hospital. In addition, under DFL 36, non-governmental organisations administering health centres are obligated to leverage an economic guarantee each year to demonstrate that they have the financial capability to fulfil their commitments, a stipulation that is impossible for Hospital Makewe to meet.

> *The State, via the Auditing Office, has a mechanism, maybe thinking about private companies, or businesses, they're not thinking about Indigenous people, where if you need 100 million pesos (approximately 200,000AUD), you have to give 10% or 20% as a guarantee; so you need to have that cash. So that means, if you're applying for 100 million pesos, you have to have 10 million pesos if it were 10% and if it's 20%, 20 million pesos; but they're all farmers and Mapuches, where are they going to get 20 million pesos from?....So in reality you're imposing this requirement that you know they're not going to meet. (Administrator)*
>
> *I don't know how it's going to be resolved…because if they demand this money from all the Mapuche organisations to be able to create health policy within their territory it's going to be damaging because as I said at the beginning, the Mapuche people are impoverished, if*

*they don't have the money they're not going to be able to do it because of this policy. (Administrator, member of the Association)*

In both formal interviews and informal conversations, key informants described the hospital as a setting characterised by a severe lack of resources and certainty. A repeated theme raised was frustration with seemingly arbitrary decisions made by State agents that had a profound impact on the ability to plan appropriately and meet contractual obligations.

*They tell us, "Okay, for the next year we're going to give you the budget for this year plus the infractor," as they call it, which is like a readjustment of the budget, which in this case was some 3.5% readjustment and always, I don't know where they get this infractor percentage from which is always below the CPI, the consumer price index. Or maybe we tell them, "It's impossible, you're giving me 3.5%, on the other hand the CPI is 5% and moreover the public sector workers have an agreement with the State for a salary hike of 6%"….That's what maybe doesn't quite make sense to us. (Administrator)*

The combination of the centralised nature of the Chilean government and the Hospital's reliance on State funding meant that the Hospital's agenda was set by State agents in Santiago, which was then handed down through Health Department. Perpetually being short of funding, the unpredictable nature of the budget and a lack of mechanisms to allow Mapuche organisations to meaningfully negotiate with the broader system thwarted attempts to engage in long-term planning and constrained the Hospital's ability to identify and align priorities with their own identified needs.

*For example… How many patients per hour? What is being administered? What are the objectives we have to reach? How many patients have to be in which program? What is your population? These are all the parameters the Health Department measures us by. I can show you statistics, for us the most important thing in the month to be able to receive*

*the salaries are the statistics. …There's never been total freedom or autonomy to be able to do or decide. (Administrator)*

One staff member explicitly linked the influence exerted on the Hospital by way of financial structures and the Association's position that advocacy is a central part of its mission.

*If I don't have the resources, not even for the minimum, which is the biomedical, when will I have the calm to be able to think? I think the solution is political negotiation. (Administrator)*

This advocacy takes three forms: strengthening the voices of Mapuche service providers, the establishment of networks between governmental, non-governmental and community organisations and engagement with political actors to improve the policy environment in relation to Mapuche health. Collectively, these actions were visualised as being part of the concept of community participation insofar as they aimed to increase the power of community organisations to act autonomously, respond to local needs, and push against the top-down imposition of planning frameworks.

*In fact, for example…I was going to make a journey to Santiago, Valparaiso to go and tell them our needs, to go and tell the Ministry, the politicians there what are our necessities and the failures of the State that hasn't allocated resources here and I'm going to do it, I'm planning…Why? Because there are a lot of things that the Chilean State, no, no, because in other places they have it, why is it that this hospital doesn't have it? Because we're Mapuche? Because it's a Mapuche organisation? We feel discriminated against in relation to other hospitals, I'll tell you the truth…And we're working with more vulnerable people, my professionals should be paid better than professionals in other places… (Director of Makewe Hospital, President of the Association)*

The following quote serves to underscore the use of political advocacy to enhance the legitimacy within State spheres not only of Makewe Hospital and its administration but of Mapuche organisations as a whole.

> *And from there the idea was born, in me at least, that we couldn't stay marginalised in Makewe, we have to in some way make the organisation that administers Makewe, the Mapuche organisation, visible, in other areas…And that's important, the visibility of the organisation so that the State or the current ministers that come in know that we exist and that we're moving forward in the field of health, intercultural health and that we want to contribute rather than detract, we want to add rather than take away….. (Administrator, member of the Association)*

**Discussion**

Indigenous governance and participation in health intersect with the rights to self-sovereignty, autonomy and health equity. These principles are therefore central to many of the underlying values of Indigenous-centred health care models, which include political and social equity and cultural strengthening and retention.[21,27-29] Similarly to community-controlled Indigenous health services worldwide, interviewees saw the role of the Association, in part, as strengthening Mapuche self-determination and social, political and economic development through appropriate health service provision.[21-23]

Taken as a whole, the interviews with staff of Makewe Hospital highlighted a dual discourse around community participation and the relationship between the Hospital and the State: interviewees spoke about the responsibilisation of communities on the one hand and on the other, a desire to increase Mapuche autonomy through the assumption of roles that allow for

engagement and representation within the Chilean State. 'Responsibilisation' refers to the process by which communities assume both the risks and responsibilities for functions in ways that reduce the scope of the government while continuing to maintain government control.[5,7] The Chilean government's obligations regarding health care provision are underpinned by as the right to health as enshrined in the Chilean constitution as well as through national legislation.

The tension between responsibilisation and autonomy of Indigenous communities has been previously explored with respect to intercultural health in Chile[24-26] and reflects the contradictory nature of participatory forms of governance more generally. That is, seen through the governmentality framework, communities and community organisations balance the desire for autonomy with ongoing dependence on governmental funding, or working within governmental systems. State power is reproduced through the same processes by which the government devolves decision-making, management and governance to communities and civil society.[4] Corresponding processes are those by which the State shifts responsibility for service provision to communities and community organisations, but retains control of the ways service is provided through imposition of regulations and obligations, normally tied to financial arrangements.[5] Through this lens, the use of audits and other forms of financial accountability measures serve to ensure that community organisations continue to adhere to the regulations set by the government and force such organisations to prove their ongoing capacity to govern.[5,19] For Indigenous health organisations, this has particular implications, as this form of governance impinges on the ability to develop autonomy and realise the objective of self-determination.[25,34] Historically, Indigenous organisations and communities have borne the brunt of accountability in terms of being expected to justify funding received by their respective governments in the form of onerous reporting requirements and other mechanisms to demonstrate legitimacy.[35] As seen in the case of Makewe Hospital, this has the effect of reducing community capability to respond to local needs and maintaining State control over resource allocation, as funding obligations are tied to those priorities determined by the State.

Although evidence indicates that the incorporation of Indigenous governance in health planning may make an important contribution to increasing health equity,[33] health policymaking processes in Chile do not allow for systematic input or shared decision-making by Indigenous communities and organisations. This institutional barrier constrains the impact of any community participation processes undertaken at local levels. There was consistent agreement across the interviewees that the failure of the Chilean State to facilitate Mapuche governance in health placed extreme limitations on the extent to which community participation could be realised, as administering Mapuche organisations had few avenues to either influence policy or develop localised responses to community needs. Because no mechanisms exist to enable Indigenous governance in health, the Association's administration of the Hospital was facilitated through DFL 36 and therefore treated as a private entity, with all the attendant obligations and responsibilities. However, the expectations of a private health provider do not correspond with the reality of the Hospital's situation and do not recognise the high level of time and resources necessary to provide adequate service within this context. Nor are there mechanisms to provide additional resources to reflect the high needs and vulnerability of the attending population. The centralisation of the Chilean government compounds the issue, as the required health programs are determined at the national level, leaving little possibility of responding adequately to particular local contexts.

In response to these tensions, the Association strives to influence broader policy both within and outside of the health care sector to improve Indigenous development. In particular, the need to position Mapuche communities and organisations as active participants in policy- and decision-making processes was a primary motivating factor as articulated by staff interviewees and the capacity to make improvements to quality of care was situated within this framing. As outlined above, the model adopted by Makewe Hospital was largely driven by the desire to increase Mapuche autonomy and visibility within the Chilean State, while at the same time being financially dependent on the State. For these reasons, political advocacy at multiple levels and in various forms was incorporated into processes of community participation. Political advocacy is a

recognised aspect of community participation, as efforts to reimagine and reorient institutional frameworks in a way that creates space for the incorporation of community perspectives and values is a shared goal. This is particularly the case when the community in question is marginalised.[39]

ILO 169, to which Chile is a signatory, obligates governments to 1) consult with Indigenous peoples 'through appropriate procedures and in particular through their representative institutions,' regarding legislative and administrative issues that affect them and 2) allow Indigenous peoples to participate in 'the formulation, implementation and evaluation of plans and programs for national and regional development which may affect them directly.'[9] This is coupled with the right to appropriate healthcare outlined in Article 7 Law 20.584, The rights and responsibilities of the patient in relation to health care (Title: *Regula los derechos y deberes que tienen las personas en relación con acciones vinculadas a su atención en salud*), was enacted in 2012. Article 7 of the law establishes the right of Indigenous peoples to receive medical attention that is culturally appropriate with respect to public institutions of care including public hospitals, health centres, family health centres (*Centros de Salud Familiar*, CESFAM) and rural health centres (*postas*) when situated in areas with high Indigenous populations. The establishment of adequate mechanisms for Indigenous governance and decision-making in health is necessary for the fulfillment of these obligations.

Limitations

A possible limitation concerns the positioning of the researcher who undertook data collection (ASF). ASF is neither Mapuche nor Chilean. However, it is difficult to say how the researcher's

outsider status may have affected the data provided by interviewees and the following interpretation. It may be that being removed from the Hospital allowed interviewees to be more open, as she may have been perceived to be more impartial and the risk of negative ramifications may have been perceived to be lower than if she were directly connected to the Hospital. On the other hand, interviewees may have been inclined to be less open with an outsider.[42] This outsider status, coupled with the researcher speaking Spanish as a second language, may also have limited the researcher's ability to fully interpret the data.

These limitations were addressed in a number of ways. First, the fieldwork period was over a year, enabling the researcher to 1) become more familiar with the context as a whole, 2) engage in many informal conversations in addition to the formal interviews, both of which supported a more complete understanding of the issues involved and 3) develop personal as well as professional relationships based on trust and mutual respect. In addition, one of the other authors (AMO) is based in Chile, in a recognised expert in the field of intercultural health, has had a professional relationship with Makewe Hospital spanning 20 years and lent her support in interpreting the data, including assisting with translation.

**Conclusions**

In the case of Makewe Hospital, the intertwinement between processes that take place between the Mapuche community and the Hospital and those situated in the wider realm of the health system demonstrate the ways that State processes and structures can serve to constrain community participation and representation. There is therefore a need for policy and legislative mechanisms that facilitate and recognise Indigenous governance in health. This would allow for the creation of policies that correspond to the reality of health service provision to Mapuche communities by Mapuche organisations, create space for the systematic input and shared decision-making by Indigenous communities and organisations and possibly ease some of the

burden currently experienced by Mapuche service providers attempting to fulfil inappropriate contractual obligations. The advocacy work engaged in by the Association is a way to navigate the tensions described by staff between the responsibilisation of communities on the one hand and on the other, a desire to increase Mapuche autonomy through engagement and representation within the Chilean State.

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