SAMUEL CENTRE FOR SOCIAL CONNECTEDNESS

SeeChange

Placing Communities First in Health Crisis Responses

Identifying and implementing best practices for community-based health responses

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EXECUTIVE SUMMARY

Latin America is the most unequal region in the world in terms of income inequalities, and struggles with deep and persistent health inequities. Some of these health inequities, however, can be addressed via community-based approaches to health, which are rooted in the knowledge, expertise, values, and needs of the community itself, and which involve community members in the research, development, and implementation processes. Community-based approaches to health, in opposition to predetermined, top-down approaches, are necessary if the deeply entrenched health inequalities facing underserved groups in Latin America and globally are to be combatted.

This report seeks to identify the ways in which communities can best be centred in responses to health crises like COVID-19, and outlines the importance of community-based responses to health more generally. A literature review of community-based health responses in Latin America, interviews with 7 individuals with experience in community-based research and/or health interventions, 6 interviews conducted previously by SeeChange Initiative, and a community engagement initiative inform the findings of this report.

Six recommendations are made in light of these findings: (1) governments and formal healthcare providers should work with communities to develop community-based responses to COVID-19 and other health and wellbeing issues; (2) intercultural community-based health and wellbeing programming should be developed in consultation and collaboration with Indigenous stakeholders; (3) organisations should meaningfully include people with disabilities in community-based health responses; (4) intergenerational approaches to community-based health responses should be promoted, privileging the knowledge and voices of older people as well as young (5) women leaders should be elevated as leaders in community-based responses in context-appropriate ways; and (6) the barriers to community members' participation in health responses should be removed by providing transportation and online access, particularly during the pandemic.

TERMINOLOGY

- The term **‘vulnerabilised’** is used by SeeChange Initiative to refer to groups and communities who have been made vulnerable by histories and legacies of colonialism, racism, and extractivism. The vulnerabilised groups focused on in this report are: Indigenous peoples (particularly Indigenous women), ethnic minority people, migrants, refugees and asylum seekers.
- **‘Social connectedness’** refers to a feeling of belonging and being connected with others. According to the Samuel Centre for Social Connectedness (SCSC), a socially connected society is one where ‘everyone – no matter their age, race, gender, sexual orientation, ability, or political affiliation – has the opportunity to belong.’[1]

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[1] Samuel Centre for Social Connectedness. 2021. *Who We Are.* Available from: https://www.socialconnectedness.org/about-us/ (Accessed 10 August 2021).

INTRODUCTION

The COVID-19 pandemic has shone a spotlight on the vast inequalities and injustices in access to healthcare and health outcomes, both between and within countries. Latin America is the most unequal region in the world in terms of income distribution,[2] and struggles with deep and persistent health inequities.[3]The World Health Organization (WHO) defines health inequities as 'differences in health status or in the distribution of health resources between different groups, arising from the social conditions in which people are born, grow, live, work and age.'[4]

Indigenous communities, women and girls, ethnic minorities, and migrants and refugees – particularly those in temporary settlements – have been historically excluded from Latin American health systems,[5] and are at greatest risk from COVID-19.[6] This is because these populations, henceforth referred to as *vulnerabilised* groups, have been made vulnerable to diseases like COVID-19 due to the intersecting inequalities they face. Intersecting inequalities are group-based inequalities due to caste, race, ethnicity, religion, and gender, which overlap with each other and with economic inequalities to

[2] Comisión Económica para América Latina y el Caribe. 2019. *Panorama Social de América Latina*. Santiago: Naciones Unidas, p.3.
[3] Ana Lorena Ruano et al. 2021. 'Understanding inequities in health and health systems in Latin America and the Caribbean: a thematic series', *International Journal for Equity in Health,* 20(94).
[4] WHO. 2018. *Health inequities and their causes.* Available from: https://www.who.int/news-room/facts-in-pictures/detail/health-inequities-and-their-causes (Accessed 9 August 2021).
[5] Ana Lorena Ruano et al. 2021. 'Understanding inequities in health and health systems in Latin America and the Caribbean: a thematic series', *International Journal for Equity in Health,* 20(94).
[6] PAHO. 2020. *PAHO Director calls to protect vulnerable groups from effects of COVID-19 pandemic*. Available from: https://www.paho.org/en/news/19-5-2020-paho-director-calls-protect-vulnerable-groups-effects-covid-19-pandemic (Accessed 9 August 2020).

reinforce each other. These inequalities are deeply entrenched in historical structures and everyday social practices.[7]

The exposure of the health inequalities and exclusion facing vulnerabilised groups during the COVID-19 pandemic has prompted calls for a re-evaluation of global health and humanitarianism. More specifically, Western-imposed, top-down, copy-and-paste responses to communities' health, which have been proven not always to be effective, and in some cases even damaging to communities,[8] have come under fire.

We also know that social isolation and loneliness are social determinants of poor physical and mental health,[9] and have been exacerbated by social distancing and isolation measures during the pandemic.[10] Community-based health responses that centre the needs, experiences, and voices of the communities themselves therefore provide an adaptive solution aimed at tackling health inequities for vulnerabilised communities, reducing social isolation in doing so.

The purpose of this report is to identify the ways in which communities can best be centred in responses to health crises like COVID-19, and to understand the importance of community-based responses to health more generally. The area of focus for this report is Latin America, as many of the communities that SeeChange Initiative work with are in the region.

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[7] Naila Kabeer. 2014. 'Social Justice and the Millennium Development Goals: the Challenge of Intersecting Inequalities', *The Equal Rights Review*, 13, p.98.
[8] Ali Murad Büyüm et al. 2020. 'Decolonising global health: if not now, when?', *BMJ Global Health*, 5(8).
[9] Catherine Haslam et al. 2015. 'Social Connectedness and Health', *Encyclopaedia of Geropsychology.*
[10] Tzung-Jeng Hwang et al. 2020. 'Loneliness and social isolation during the COVID-19 pandemic', *International psychogeriatrics*, 32(10), pp.1217–1220.

The first step of conducting this research was to conduct a literature review of community-based responses to health issues in Latin America. This review sought to discover which frameworks, practices, and tools can be employed in community-based responses to health crises and challenges. Using the overarching themes identified in the literature review as a guide, in-depth and open-ended interviews were then carried out with seven individuals with experience in community-based research and/or health interventions. Their areas of expertise included: Indigenous research methodologies; community-based research on the intersection between migration and climate degradation; disability inclusion and self-determination; public health response; community-based mental health intervention; and community-based health and well-being promotion through culture.

Additionally, six interviews carried out prior to the fellowship by SeeChange Initiative with community activators[11] were analysed. Three of these interviews were with community activators about their experiences as women leaders and three were with community activators about their work as leaders in their community-led response to the COVID-19 pandemic.

Finally, the submissions from a PhotoVoice-style community engagement project, where participants submitted visual and textual reflections on their learnings during the COVID-19 pandemic, were analysed for themes. These themes, located at the intersection between social connectedness and community-based health response during the COVID-19 pandemic, then informed the report's recommendations.

[11] Activators are leaders within their communities and/or organisations who identify a need and opportunity to implement SeeChange Initiative's Community-First Roadmap in their communities.

BACKGROUND

Coloniality and Global Health

Since the pandemic began to further expose the vast global and group-based inequalities, there have been increased calls to acknowledge the existence of coloniality and Western hegemony within global health systems and humanitarianism.[12][13] Coloniality refers to the 'long-standing patterns of power that emerged as a result of colonialism, but that define culture, labor, intersubjective relations, and knowledge productions well beyond the strict limits of colonial administrations.'[14] In other words, coloniality is the modern-day articulation of colonialism.

Within global health practice, coloniality remains in the inequalities that exist between so-called high-income countries (HICs) and low-middle income countries (LMICs), as well as the within-country inequalities between groups and individuals, and the domination of Western actors and voices within global health practice and policy.[15]

Barriers to enjoying the right to health

Discrimination, driven by biases against Indigenous peoples, ethnic minority populations, women and girls, and the poor in general have been identified as obstacles preventing access to care for vulnerabilised groups and deterring many from seeking

[12] Lisa Richardson & Allison Crawford. 2020. COVID-19 and the decolonization of Indigenous public health. Canadian Medical Association Journal, 192(38).
[13] Mishal Khan et al. 2021. 'Decolonising global health in 2021: A roadmap to move from rhetoric to reform'. *BMJ Global Health* 6(3).
[14] Nelson Maldonado-Torres. 2007. 'On the Coloniality of Being', Cultural Studies, 21 (203), pp.240-270.
[15] Seye Abimbola & Madhukar Pai. 2020. Will global health survive its decolonisation? *The Lancet,* 396(10263), p.1627.

care.[16]Migrants, including refugees, asylum seekers, and internally displaced persons (IDPs) also face barriers in accessing health services in Latin America. These may be due to a lack of adequate information, legal barriers, a lack of culturally appropriate care, and healthcare providers' discrimination and prejudice towards migrants.[17][18]

The Indigenous peoples of Latin America are, of course, extremely socially and culturally heterogeneous. In total, there are approximately 45 million self-identified Indigenous people living on the land we know as South and Central America,[19] who belong to over 826 different Indigenous groups.[20]However, one determinant of Indigenous health common to all Indigenous peoples of Latin America (and Indigenous peoples globally) is the legacy of colonialism. The structural violence and sociocultural devaluation of Indigenous lives and epistemes which arose from colonialism have meant that, despite legislation aiming to protect Indigenous people's rights in Latin America, Indigenous peoples' socioeconomic conditions and wellbeing are, on average, far worse than those of non-Indigenous people.[21] Despite Indigenous peoples making up just 8% of the Latin American region's population, 14% of the Indigenous population

[16] Arachu Castro, Virginia Savage & Hannah Kaufman. 2015. 'Assessing equitable care for Indigenous and Afrodescendant women in Latin America', *Rev Panamericana de Salud Pública*, 38(2), pp.96–109.
[17] Ietza Bojorquez et al. 2021. 'Migration and health in Latin America during the COVID-19 pandemic and beyond', *The Lancet*, 397(10281), pp.1234-1245.
[18] Martha Denisse Piérola & Marisol Rodríguez Chatruc. 2020. 'Migrants in Latin America: Disparities in Health Status and in Access to Healthcare', *Inter-American Development Bank*. Available from: https://publications.iadb.org/en/migrants-in-latin-america-disparities-in-health-status-and-in-access-to-healthcare (Accessed 10 August 2021).
[19] A map of the Indigenous territories on the land that we know as South and Central, created by Native Land Digital is available at https://native-land.ca/.
[20] United Nations Department of Economic and Social Affairs, *The State of the World's Indigenous Peoples: Education, Volume 3: Education* (New York: United Nations, 2014), p.109.
[21] Cruz-Saco, Maria Amparo. 2018. 'Indigenous communities and social inclusion in Latin America', *United Nations Expert Group Meeting on Families and Inclusive Societies.* New York Headquarters, May 15-16. Connecticut College.

live in poverty and 17% live in extreme poverty,[22] a rate 2.7 times greater than the rest of the population.[23]The socioeconomic disparities experienced by Indigenous peoples in Latin America affect their access to health services, and thus their health outcomes.

ISSUE, EVIDENCE & KEY FINDINGS

A content analysis of the interviews conducted, and an analysis of the findings of the community engagement initiative revealed several key themes. These include promising practices for community-based health responses, considerations and challenges when approaching community-level research and health response, and the implications of the COVID-19 pandemic in terms of social connectedness.

A Community-Based Approach

Interview participants were asked to explain what a community-based approach to health responses or to research looked like to them (depending on their area of expertise). Most of the interviewees defined a community-based approach in terms of what it was *not*. In other words, a community-based approach was described as being in opposition to the top-down practice of organisations or individuals extending health services *to* communities or conducting research *on* communities, rather than working *with* them. All interviewees highlighted the ability of people within the community to take *ownership* of health interventions and responses or research regarding their community as vital to community-based approaches.

[22] World Bank. 2015. *Indigenous Latin America in the Twenty-First* Century (Washington, DC: World Bank) p.12
[23] Ibid., p.59.

The interviewees involved in public and community health work identified a community-based approach to health as one which meaningfully involved the communities themselves to identify their real issues and the solutions that *they* wanted to implement. These interviewees also highlighted that community-based health interventions are deployed by the community members themselves, with community leaders and knowledge holders representing vital assets in a community-based response.

Community-based approaches also involve actively including community members and facilitating their participation in all research carried out that will impact or involve them. Speaking on community-based research processes, one interviewee identified the importance of 'centring horizontal collaboration in terms of just engaging with communities and with different individuals and different groups within these communities.'[24]They also highlighted the importance of remembering and respecting the heterogeneity of communities, thus opposing the trend within global health and humanitarianism of generalising populations. Another interviewee also identified that all stakeholders and community members should have an active role in designing research that impacts their communities, as well as how the information gathered from research is stored, transmitted, and accessed.[25]

The Importance of Community-Based Approaches

[24] Linn Biorklund Belliveau. 2021. Interviewed by Alice Finta. 3 August, online.
[25] Gabrielle Hughes. 2021. Interviewed by Alice Finta. 7 July, online.

Interviewees were asked why they believed community-based approaches to health or to research were important and beneficial. The first theme identified was that predetermined, top-down approaches fail to serve communities:

> If you go to a community, with your own concept, without really understanding how they live, how they perceive disease, how they perceive access to health, and what it means to them, then you're bound to fail.[26]

Several interviewees stated that centring communities in health responses was important, precisely because they understand their own health and broader social context and issues best, and they know which resources they have and which they require.

One community activator mentioned that during the COVID-19 pandemic, organisations had come to their community and distributed resources, but had failed to teach them about preventative measures such as proper hand washing and *why* they should wash their hands, wear a mask, and maintain social distance. The interviewee noted that they themselves knew for a fact that their community needed to be informed, as well as to receive resources. They also shared that each organisation that had come to their community had come with their own way of working, without paying attention to who was working on the ground and what had already been done to achieve the same goal.[27] Several of the interviewees engaged in public health work identified this tendency of health organisations and governmental agencies to step over one another, without adequately consulting with the communities or with each other, as being counter-productive to health crisis responses and potentially harmful to communities.

[26] Samuel Bumicho. 2021. Interviewed by Alice Finta. 2 August, online.
[27] Salim Kalim. 2021. Interviewed by Alejandra Melian-Morse. 16 July, online.

Interviewees from the Friendship Bench, a Zimbabwe-based NGO working to enhance communities' mental wellbeing and quality of life through therapy delivered by trained lay workers, noted that each community's context and the situations they face are specific and unique to them. Rather than imposing programmes or interventions that are not specific to their context, a community-based approach allows organisations and communities to adjust their health interventions to the specific problems the community is facing at that time. From their experience, this allows for communities to adjust their responses to shocks and crises, such as COVID-19.[28]

A second benefit identified was that community-based health responses are more sustainable. This is because community members are able to take ownership of their own health needs and responses and, since they develop the health initiatives themselves, community members are able to lead and sustain them.

Finally, interviewees shared that community-based health responses can fill gaps in state-provided healthcare and health crisis response. State responses often neglect to take into account communities' context-specific needs and realities, and can often be hard for communities to access and somewhat institutionalised.

Respecting and Incorporating Indigenous Knowledge in an Intercultural Approach

The literature review conducted for this report revealed that intercultural approaches to health, wellbeing, and community-based research represent a promising culturally safe[29] way to combat the exclusion of Indigenous communities from

[28] Georgina Chapoterera & Charmaine Chitiyo. 2021. Interviewed by Alice Finta. 6 July, online.
[29] Cultural safety is a concept originally developed by Maori nurses,

healthcare systems in Latin America.[30] Intercultural health can be understood as the practices that bridge Indigenous and Western medicine, where both are considered as *complementary* and of equal value.[31] One interviewee also pointed out that in creating a culturally safe intercultural space, one must ensure to not only account for and respect Indigenous narratives and knowledges, but also 'understand that they have actually been […] actively suppressed' by colonial systems and actors.[32]

Strengthening Intergenerational Communication and Support

The literature review also revealed intergenerational health initiatives and collective action to be prominent in community-based health and wellbeing responses in Latin America. Furthermore, interviewees from the Friendship Bench and the Grandmother Project highlighted that elders, particularly grandmothers, represent a positive and necessary source of knowledge and potential influence within communities. As such, the interviewees suggested the value of centring elders in community-based responses and strengthening the communication channels between generations.

Supporting Women as Leaders of Community Responses

Findings from the literature review and analysis of four of the interviews called attention to the positive impacts of supporting women as leaders of community-based health responses. Women have been underrepresented in decision-making processes

[30] Doreen Montag et al. 2021. 'Healthcare of Indigenous Amazonian Peoples in response to COVID-19: marginality, discrimination and revaluation of ancestral knowledge in Ucayali, Peru', *BMJ Global Health*, 6(1).
[31] Javier Mignone et al. 2007. 'Best practices in intercultural health: five case studies in Latin America', *Journal of Ethnobiology and Ethnomedicine*, 3(31).
[32] Gabrielle Hughes. 2021. Interviewed by Alice Finta. 2 August, online.

globally. In fact, although women comprise 70% of the global health workforce, they hold just 25% of senior decision-making roles, and women in Global South countries hold less than 5% of senior leadership roles.[33]

In Latin America, structural violence against women is understood to have entered Indigenous societal dynamics partly due to gendered social norms which were transmitted by Western-imposed capitalism, and can therefore be considered a legacy of settler colonialism. In the twentieth century, the imposition of gender norms inherent within the androcentric Western capitalist model resulted in a shift away from the traditional gendered division of labour. This increased Indigenous women's economic dependence upon men, which contributed to their devaluation within Latin American society.[34] Alma, a community activator from Guatemala, explicitly referred to the devaluation of women compared to men as 'the Western part that has invaded' their community, which opposes the knowledge within their cosmovision that 'the role of women is very important, because of their wisdom and love.'[35]

In fact, several of the interviewees felt that women represent vital assets to successful community-based health responses. This is because women are often the community members who understand their communities best, act as caregivers the most, and who drive the social activities and social cohesion most within communities. These findings were also supported by the interviews conducted by SeeChange Initiative with their community activators:

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[33] Kim Robin van Daalen et al. 2020. 'Symptoms of a broken system: the gender gaps in COVID-19 decision-making. *BMJ Global Health,* 5(10), p. 13.
[34] Linda Green. 1999. *Fear as a way of life.* New York, NY: Columbia University Press.
[35] Alma Temaj. 2021. Interviewed by Megan Corbett-Thompson. 18 February, online. Translated by Megan Corbett-Thompson and Jessica Farber.

> We are the ones who take care of the homes, and because we know what is needed, how to share and use this. Most importantly, we are always caring for and making sure that our families are safe and healthy. We have the most awareness about health in our homes. And, well, we are more organised.[36]

Historical and Intergenerational Trauma

When prompted, several of the interviewees engaged in community-based health or research stated that it is important to be cognisant of the previous events that a person or community have faced in relation to trauma, as well as how they understand, experience, and manage issues relating to trauma. All of the interviewees that spoke about trauma drew upon past examples of communities they had worked with, or knew of, to illustrate how historical and intergenerational trauma can significantly impact people. However, two of the interviewees cautioned that those intending to work with communities must be cautious not to construe community members as victims, but rather, to acknowledge the different types of potential trauma and oppression community members may have experienced, alongside their resilience, power, and knowledge as people.

Including People with Disabilities

Over 70 million people with disabilities live in the Latin American and Caribbean region, and they are among the most excluded populations, facing high levels of poverty and unemployment.[37] People with disabilities face increased barriers to accessing

[36] Gissela Rodas. 1. 2021. Interviewed by Jessica Farber. 18 February, online. Translated by Megan Corbett-Thompson and Jessica Farber.
[37] Economic Commission for Latin America and the Caribbean. 2020. *Regional report on measuring disability: overview of the disability measurement procedures in Latin America and the Caribbean*.

healthcare, particularly in low and middle-income countries.[38] A survey conducted among representatives of civil society organisations (CSOs) of people with disabilities from 16 Latin American countries found that 76% of respondents said that their governments had not consulted people with disabilities or encouraged their participation in the decision-making process for COVID-19 responses. This is despite the majority of the Latin American nations' COVID-19 response strategies listing people with disabilities among those groups most vulnerable to COVID-19.

The literature review conducted for this report revealed a serious lack of data regarding the inclusion of people with disabilities in community-based research, approaches, and/or specific approaches to health in Latin America. The simple answer that Hezzy Smith, director of advocacy initiatives at the Harvard Law School Project on Disability, gave when asked how to ensure that people with disabilities are included in community-based responses to health was that *people need to care*.

> You value what you measure and you measure what you value. And if you're not actively looking for people with disabilities, because of pervasive barriers, especially in developing settings, you're going to be much less likely to find them. [39]

This interview revealed that the exclusion of people with disabilities from public health initiatives and the discrimination against people with disabilities in the

Available from: https://repositorio.cepal.org/handle/11362/36945?locale-attribute=en (Accessed 10 August 2020).

[38] Tess Bright & Hannah Kuper. 2018. 'A systematic review of access to general healthcare services for people with disabilities in low and middle income countries', *Int J Environ Res Public Health*, 15(9), p.1879.

[39] Hezzy Smith. 2021. Interviewed by Alice Finta. 31 July, online.

development sector is seen as ‘permissible and reasonable’, despite being ‘discriminatory and exclusionary’. As a result, the cost of disability is ‘externalised to the people with disabilities.’[40] In terms of how organisations can go about including people with disabilities in their responses, Hezzy identified the need for every organisation to be in contact with at least one disabled people’s organisation (DPO). By creating a register of local DPOs to consult when conducting outreach or research, for example, organisations can systematically address disability issues in a competent way.

Social Connectedness and COVID-19

In addition to conducting and analysing interviews and conducting a literature review, a community engagement initiative involving an intergenerational PhotoVoice-style project was held as part of this research project. This project was designed to provide a platform for young people and older people to share their experiences and to learn from the experiences of others by taking photos and sharing their reflections. SeeChange Initiative’s community members were invited to share a photograph and caption, in English or in Spanish, reflecting on what they had learned over the past year of the pandemic, and to discuss their takeaways in a group setting. The main themes identified from the initiative are presented in the word cloud below (figure 1).

The overriding theme of the responses was that living through the COVID-19 pandemic had reminded respondents of the importance of human connection, particularly the importance of connecting with family members. Time spent physically

[40] Hezzy Smith. 2021. Interviewed by Alice Finta. 31 July, online.

with family, talking with family online, and sharing in one's culture were shown to be important to respondents. Connecting with family and with friends helped many of the respondents to cope with the anxieties and loneliness they associated with isolation measures during the pandemic.

Figure 1: Word map of community engagement responses

RECOMMENDATIONS

The following recommendations are based on the findings of the primary and secondary data gathered for this report, as outlined in the previous section. Since this research project focused on community-based approaches to health in Latin America,

these recommendations have been created with the Latin American region in mind. However, they remain relevant and translatable to other contexts.

National, provincial, and local governments and formal healthcare providers

Recommendation #1: Work with communities to develop responses to COVID-19 and other health and wellbeing issues that centre the needs, resources, and culture of communities as identified by them.

- This report has highlighted the importance of community-based health responses. Top-down and predetermined health responses which do not take into account communities' specific contexts and histories are often ineffective in improving community health and, if cultural safety is not ensured, can also be seriously damaging to their psychosocial wellbeing. Community *ownership* of health responses should be promoted by centring communities' voices, experiences, and understandings of health and wellbeing in the design and implementation of health responses. This is vital for all stakeholders who wish to reduce the health inequalities between vulnerabilised groups and the rest of the population. Additionally, community-driven responses are more sustainable than top-down approaches imposed by outside actors, resulting in long-lasting positive health outcomes.

Recommendation #2: Develop intercultural community-based health and wellbeing programming, in consultation with Indigenous experts, which recognises and promotes traditional Indigenous knowledge.

- This would involve incorporating both Indigenous and so-called 'Western biomedical' practices and knowledge regarding health, medicine, and wellbeing into an intercultural approach. Relevant stakeholders must be equally included in all processes of research, development, and implementation. Intercultural approaches to health and wellbeing represent a significant advancement of the right to belong[41] of Indigenous peoples.[42]

Civil society organisations working on community health

Recommendation #1: Meaningfully include people with disabilities when developing community-based health interventions and responses.

- This report has presented an overview of the statistics regarding the exclusion of people with disabilities from health and wellbeing programming and responses in Latin America. It cannot, however, speak to the very real human impact of the systemic exclusion of people with

[41] The right to belong is defined by Kim Samuel as 'a framework for thinking about how to build dignity across the social, economic, and political domains', and about their right 'to maintain a living cultural heritage as a minority community.
[42] Kim Samuel. 2019. *Realizing the Human Right to Belong.* Available from: https://kimsamuelcanada.medium.com/realizing-the-human-right-to-belong-bb9dc0f6a896 (Accessed 8 August 2021).

disabilities from health systems and responses across the world and the impact of this in terms of social isolation and their right to belong. CSOs working on community health should therefore recognise the need to include community members with disabilities as a matter of priority in all community-based health research, responses, and interventions. At the minimum, CSOs should create a register of local disabled people's organisations whom they should consult when conducting research or outreach with communities.

Recommendation #2: Incorporate the knowledge and voices of older community members in participatory research and decision-making, in an intergenerational approach to community-based health responses.

CSOs and actors involved in public health programmes often focus on younger people and youth groups, to the detriment of the older generations. CSOs involved in community health should recognise that community elders are a positive and essential source of knowledge and influence within communities and thus represent an invaluable asset in community-based responses.

- In order to facilitate an intergenerational approach to communities' health and wellbeing, CSOs should work to strengthen the communication channels between the generations. This can be done, for example, by facilitating intergenerational sharing circles, focus groups, or community meetings to foster knowledge sharing and discussion between people of

all generations, and by creating intergenerational solidarity networks. By promoting intergenerational social connectedness through collaborative capacity building strategies such as these, entire communities' capacity to respond to health issues can be greatly strengthened.

Recommendation #3: Develop context-appropriate ways to support and uplift women leaders in community-based health responses.

- This research has found that women represent an important asset to community health responses, given that they tend to hold positions as knowledge holders, caregivers, and drivers of social activities and cohesion within their communities. As such, CSOs should support women community leaders as drivers of communities' health and wellbeing responses and resources by working to provide them with context-appropriate resources and helping to strengthen their social networks, including with relevant outside stakeholders.

Recommendation #4: Remove barriers to community members' participation in health responses by providing transportation and online access.

- This final recommendation is a practical one. CSOs working on community health issues should seek to facilitate community members' active participation in community-based research, discussions, and programme implementation. This may involve providing or sourcing transportation

where needed, particularly in rural areas. In the context of the COVID-19 pandemic, access to the internet and online connection has become critical, as evidenced by the responses to the community engagement initiative. Organisations should therefore work to facilitate communities' online connection where possible, and work to include community members without internet connection in research, discussions, and programme implementation. This includes ensuring that key health messages are delivered to all members of the community.

IMPACT

At the governmental level, the value of community-based health approaches in terms of reducing health disparities for underserved populations should be formally recognised. Governments and leaders in formal healthcare provision can then implement, fund, and support community-based health programmes which draw on communities' existing knowledge and social networks as key assets. Furthermore, governments should recognise and act upon the value of an intercultural approach to health which respects and promotes traditional Indigenous knowledge. The Guatemalan government's Inclusive Model of Health serves as an example of an intercultural health model designed to address health disparities among Indigenous communities. This model hinges on the right to health, gender perspectives, intercultural awareness, and

mother nature.[43] In the context of COVID-19, initiatives regarding COVID-19 spread and prevention, the mental health impacts of the pandemic, and vaccination programmes should be community-centred in order to ensure communities' health and wellbeing in a culturally safe and sustainable way.

At the local level, CSOs such as the Samuel Centre for Social Connectedness (SCSC) can advocate for the recognition and adoption of approaches to health that centre communities' voices and needs. This is relevant not only in response to the COVID-19 pandemic, but also in regards to other health crises and chronic health matters that particularly affect underserved and vulnerabilised communities.

CSOs involved in community health, like SeeChange Initiative, can focus on meaningfully including people with disabilities by explicitly including their needs when developing their approaches and by building partnerships with local disabled people's organisations.

CSOs like SeeChange can also help communities to create and participate in intergenerational participatory research projects, like the one conducted for this report, and facilitate intergenerational knowledge-sharing. In the future, intergenerational participatory research and knowledge-sharing initiatives could be scaled up by SeeChange, and targeted in order to understand community members' experiences and needs during health crises. Pursuing an intergenerational approach to communities' health will result in better-informed and stronger health responses and will help

[43] Ministerio de Salud Pública y Asistencia Social. 2020. *El Modelo Incluyente de Salud (MIS).* Available from: https://www.mspas.gob.gt/institucional/modelo-incluyente.html (Accessed 10 August 2021).

community members of *all* ages to find the power within to tackle health crises like COVID-19.

CONCLUSION

The COVID-19 pandemic has profoundly exacerbated existing health inequalities. As a result, health approaches which place the context-specific needs, knowledge, and voices of communities affected at the forefront in culturally safe and sustainable responses, thus helping to combat health inequalities, are more necessary than ever.

This report highlighted the value of community-based approaches and responses to health and identified several promising practices for centring communities in responses to their health issues.

A literature review of past community-based responses and approaches to health-related topics in Latin America guided the report and the primary interview topic guides. Interviews with individuals with experience in community-based research and/or health interventions discovered what community-based responses meant to them and identified several overarching themes. These were: the importance of community-based approaches; intercultural approaches; promoting intergenerational approaches; women as leaders of health responses; historical and intergenerational trauma; including people with disabilities; and communities' perceptions of COVID-19 and its link to social connectedness. Interviews with SeeChange Initiative community activators were also

analysed to provide an understanding of how community members who are involved in community-based health responses experience doing so.

In future participatory research, vulnerabilised groups, including Indigenous peoples, migrants, refugees, and asylum seekers, women and girls, people with disabilities, and LGBTQ+ groups should also be included, and disaggregated data regarding the impact of COVID-19 on these groups prioritised.

Moving forward, the promising practices identified in this report can be applied to community-based approaches to COVID-19 prevention and post-COVID recovery. With COVID-19 vaccines finally arriving in the communities that need them most in Latin America and elsewhere, community organisations, healthcare providers, and governmental actors must ensure that communities are centred in vaccine rollouts. In order to tackle the health and social inequities aggravated by the COVID-19 pandemic, top-down, indiscriminate, and culturally unsafe approaches to COVID-19 vaccination delivery and information dissemination must be avoided at all costs.

BIBLIOGRAPHY

Abimbola, Seye & Pai, Madhukar. 2020. Will global health survive its decolonisation? *The Lancet,* 396(10263), p.1627.

Aubel, Judi. 2021. Interviewed by Alice Finta. 10 August, online.

Biorklund Belliveau, L. 2021. Interviewed by Alice Finta. 3 August, online.

Bojorquez, Ietza et al. 2021. 'Migration and health in Latin America during the COVID-19 pandemic and beyond', *The Lancet*, 397(10281), pp.1234-1245.

Bright, Tess & Kuper, Hannah. 2018. 'A systematic review of access to general healthcare services for people with disabilities in low and middle income countries', *Int J Environ Res Public Health*, 15(9), p.1879.

Bumicho, Samuel. 2021. Interviewed by Alice Finta. 2 August, online.

Büyüm, Ali Murad et al. 2020. 'Decolonising global health: if not now, when?', *BMJ Global Health*, 5(8).

Castro, Arachu, Savage, Virginia & Kaufman, Hannah. 2015. 'Assessing equitable care for Indigenous and Afrodescendant women in Latin America', *Rev Panamericana de Salud Pública*, 38(2), pp.96–109.

Chapoterera, Georgina. & Chitiyo, Charmaine. 2021. Interviewed by Alice Finta. 6 July, online.

Comisión Económica para América Latina y el Caribe. 2019. *Panorama Social de América Latina*. Santiago: Naciones Unidas.

Cruz-Saco, Maria Amparo. 2018. 'Indigenous communities and social inclusion in Latin America', *United Nations Expert Group Meeting on Families and Inclusive Societies.* New York Headquarters, May 15-16. Connecticut College.

Economic Commission for Latin America and the Caribbean. 2020. *Regional report on measuring disability: overview of the disability measurement procedures in Latin America and the Caribbean*. Available from: https://repositorio.cepal.org/handle/11362/36945?locale-attribute=en (Accessed 10 August 2020).

Green, Linda. 1999. *Fear as a way of life.* New York, NY: Columbia University Press.

Haslam, Catherine et al. 2015. 'Social Connectedness and Health', *Encyclopaedia of Geropsychology.*

Hughes, Gabrielle . 2021. Interviewed by Alice Finta. 7 July, online.

Hwang, Tzung-Jeng et al. 2020. ‘Loneliness and social isolation during the COVID-19 pandemic’, *International psychogeriatrics*, 32(10), pp.1217–1220.

Jiménez Montejo, Micaela. 2021. Interviewed by Alejandra Melian-Morse. 15 July, online.

Jiménez Montejo, Micaela. 2021. Interviewed by Megan Corbett-Thompson. 18 February, online.

Kabeer, Naila. 2014. ‘Social Justice and the Millennium Development Goals: the Challenge of Intersecting Inequalities’, *The Equal Rights Review*, 13, pp.91-116.

Kalim, Salim. 2021. Interviewed by Alejandra Melian-Morse. 16 July, online.

Khan, Mishal. et al. 2021. 'Decolonising global health in 2021: A roadmap to move from rhetoric to reform'. *BMJ Global Health* 6(3).

Maldonado-Torres, Nelson. 2007. ‘On the Coloniality of Being’, *Cultural Studies*, 21 (203), pp.240-270.

Mignone, Javier et al. 2007. 'Best practices in intercultural health: five case studies in Latin America', Journal of Ethnobiology and Ethnomedicine, 3(31).

Ministerio de Salud Pública y Asistencia Social. 2020. *El Modelo Incluyente de Salud (MIS)*. Available from: https://www.mspas.gob.gt/institucional/modelo-incluyente.html (Accessed 10 August 2021).

Montag, Doreen et al. 2021. 'Healthcare of Indigenous Amazonian Peoples in response to COVID-19: marginality, discrimination and revaluation of ancestral knowledge in Ucayali, Peru', *BMJ Global Health*, 6(1).

Native Land. 2021. *Native Land*. Available fromhttps://native-land.ca/: (Accessed: 11 August 2021).

PAHO. 2020. *PAHO Director calls to protect vulnerable groups from effects of COVID-19 pandemic*. Available from: https://www.paho.org/en/news/19-5-2020-paho-director-calls-protect-vulnerable-groups-effects-covid-19-pandemic (Accessed 9 August 2020).

Piérola, Martha Denisse & Rodríguez Chatruc, Marisol. 2020. ‘Migrants in Latin America: Disparities in Health Status and in Access to Healthcare’, *Inter-American Development Bank*. Available from:

https://publications.iadb.org/en/migrants-in-latin-america-disparities-in-health-status-and-in-access-to-healthcare (Accessed 10 August 2021).

Richardson, Lisa & Crawford, Allison. 2020. COVID-19 and the decolonization of Indigenous public health. *Canadian Medical Association Journal*, 192(38).

Rodas, Gissela. 2021. Interviewed by Alejandra Melian-Morse. 19 July, online.

Rodas, Gissela. 2021. Interviewed by Jessica Farber. 18 February, online.

Ruano, Ana Lorena et al. 2021. 'Understanding inequities in health and health systems in Latin America and the Caribbean: a thematic series', *International Journal for Equity in Health,* 20(94).

Samuel Centre for Social Connectedness. 2021. *Who We Are.* Available from: https://www.socialconnectedness.org/about-us/ (Accessed 10 August 2021).

Samuel, Kim. 2019. *Realizing the Human Right to Belong.* Available from: https://kimsamuelcanada.medium.com/realizing-the-human-right-to-belong-bb9dc0f6a896 (Accessed 8 August 2021).

Smith, Hezzy. 2021. Interviewed by Alice Finta. 31 July, online.

Temaj, Alma. 2021. Interviewed by Megan Corbett-Thompson. 17 February, online.

United Nations Department of Economic and Social Affairs, *The State of the World's Indigenous Peoples: Education, Volume 3: Education* (New York: United Nations, 2014): 109.

Van Daalen, Kim Robin et al. 2020. 'Symptoms of a broken system: the gender gaps in COVID-19 decision-making. *BMJ Global Health*, 5(10), p.13.

WHO. 2018. *Health inequities and their causes.* Available from: https://www.who.int/news-room/facts-in-pictures/detail/health-inequities-and-their-causes (Accessed 9 August 2021).

World Bank. 2015. *Indigenous Latin America in the Twenty-First* Century (Washington, DC: World Bank).