Intentional Co-Design: Our Experience-Based Approach To Advancing Health and Racial Equity

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Since its founding in 1996, Health Leads has worked with communities, community advocates[1] and system leaders[2,3] to improve the health of under-resourced populations. Over that period, we've learned repeatedly that **solutions are strongest when they are designed with and led by communities.**[4–7]

In parallel, numerous ideas have gained traction in health, such as the social determinants of health, asset-based approaches, systems change, structural racism, community capacity, and community power.

In this white paper, we take an evidence-informed look at the field from our vantage point and introduce our experience-based approach to co-design, which we call **Intentional Co-Design.**



Introduction

It is broadly accepted that designing with users leads to better products, services, and outcomes. Although the evidence varies across industries, in software design it is so strong that it has led to an ISO standard.[8] In health care delivery, where the practice has a variety of names, including 'participatory service design' or 'co-design,' a 2023 literature review by Silvola and colleagues summarized the evidence across three overlapping areas:[9]

1. Performance: Co-design is associated with improvements in efficiency, quality of care and clinical outcomes.
2. Experience: Co-design creates better patient-centered experiences capable of positively impacting the quality of services, satisfaction, and perceived value.
3. Value: Co-design is associated with enhanced accessibility, as well as improvements in the quality and efficiency of health care processes.

As Silvola and colleagues say, their review builds on previous research showing that co-design is effective at creating processes for health care professionals to refer patients to various local support groups with the potential to improve health and well-being.[10] However, other research has suggested that co-design processes need to better adhere to evidence-based approaches[11] and be more attentive to the experience of service users participating in the co-design process[12] for the practice to be more thoroughly assessed.

Beyond Design

While the focus of co-design in health care is usually service improvement (often within the framework of quality improvement) there are also benefits to the 'service users' involved as well as the wider system.[9] For instance, with regard to service users, co-design processes: engage patients; create positive relationships between users, caregivers, and professionals; and help patients/users better understand how the health system is organized. With regard to the wider system, co-design processes are creative – they generate ideas beyond the immediate focus for how to change processes, practices, and clinical environments to improve health services.[13,14]

This three-part set of outcomes – for the service being co-designed, the service users involved, and the wider system – coheres with broader work on the value of community engagement in health improvement. In 2010, Popay built on practice-based experience to argue that community engagement could be linked to community development,[15] a way of working that enables people to strengthen networks and identify common concerns, and supports them in taking action related to those concerns.[16] To do that, Popay argued, we need to be clear at what *level* a community is being engaged.

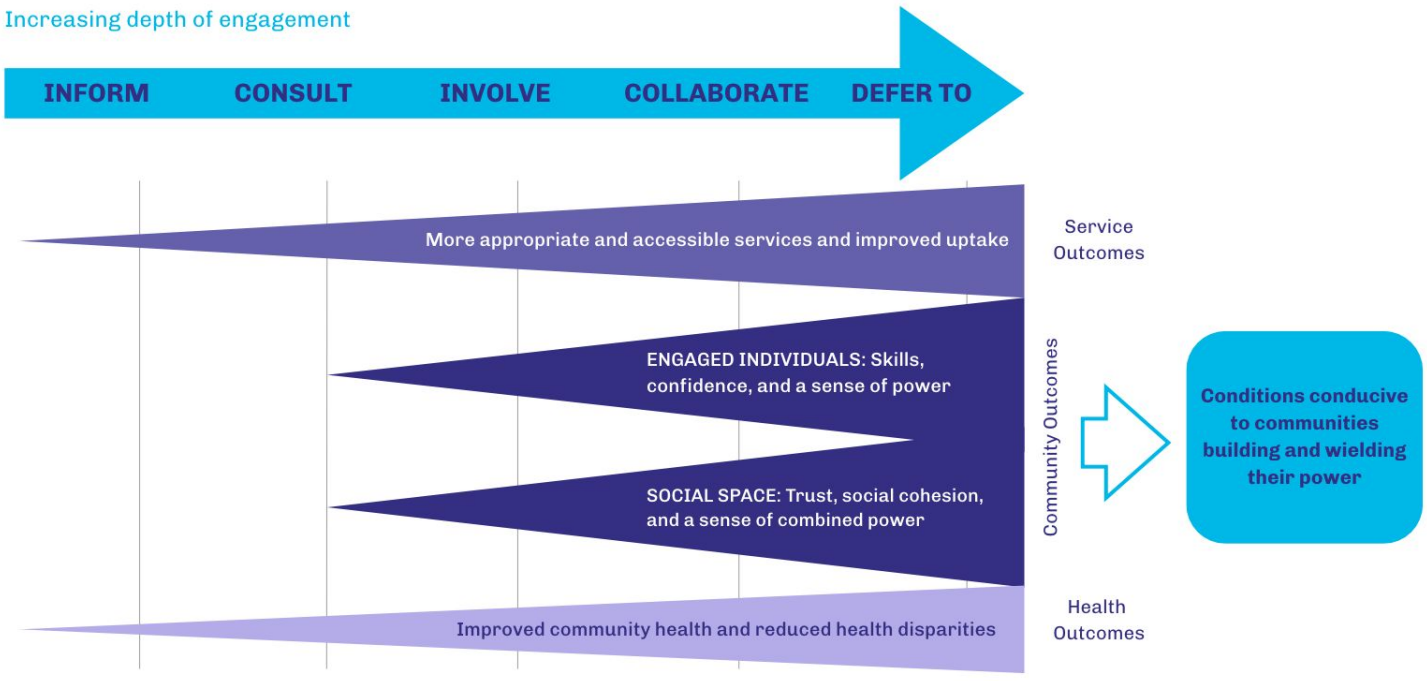
Building on work to delineate the levels,[17,18] Popay proposed that while all forms of community engagement have the potential to improve service outcomes and the health outcomes of those that access those services, deeper levels of engagement – those that involve co-production, delegating some power to communities, or giving community direct control – generate social outcomes, such as enhanced social capital, which have the potential to improve the health of the wider community, not just those 'engaged'.



In 2022, Iton and colleagues built on a review of the literature linking community power and health[19] to propose a refinement of Popay's model, specifically that deeper levels of engagement impact the community members engaged and the social space between them.[20] The community members developed their skills, confidence, and sense of power. And the changes to the social space related to levels of trust and social cohesion. Combined, these changes, according to Iton and colleagues, create the conditions for communities to build and wield their power (see Figure 1).

Figure 1: The Breadth of Outcomes Associated with Co-Design

As engagement with communities deepens outcomes extend beyond service and health



Community power is key to health. It has been described as both fundamental and instrumental.[21] Fundamental refers to the observation that it builds community confidence, capacity, and efficacy, all of which contribute to a sense of coherence and control, both of which are known to underpin health.[22,23] Instrumental refers to the observation that communities with power are able to bring about structural changes to make society fairer and more just, which reduces inequities.[20,24]

All in all, while designing with users improves software design, in health, when done well,[11] it has the potential to go far beyond service design.

The Importance of Listening

In our experience, at the heart of co-design is listening – specifically, people working within systems listening to the users of those systems. On the face of it, this is obvious but the importance of listening has a number of layers to it (See Figure 2).

The Immediate Layer

In health, co-design is often advocated for conditions and services in which there are disparities in outcomes between user groups. The argument – well-made in other disciplines, such as social work[25] – is that users have essential expertise that people within systems are not aware of. Being aware of this knowledge – through listening – has the potential to ensure that services are better tailored to users, especially those enduring poorer health outcomes.

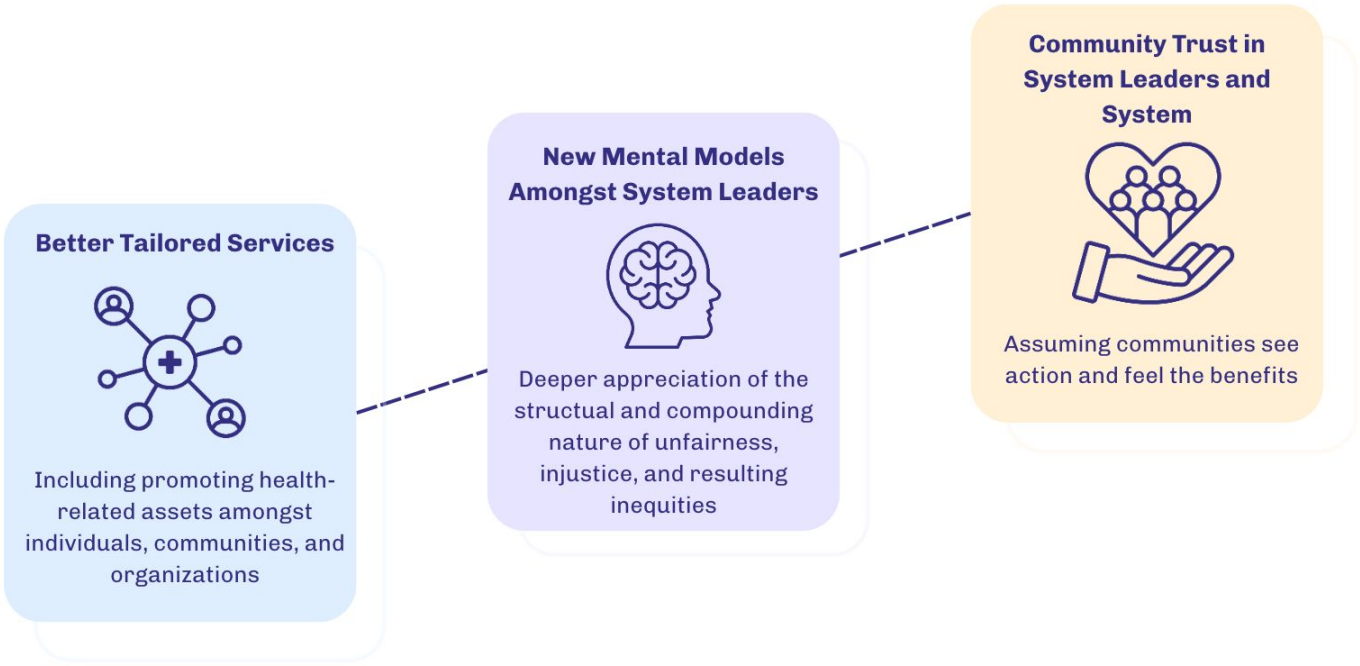
Related to this is the observation that health systems tend to think about groups on the basis of their problems, often called their deficits. However, this approach ignores the many positives that groups have, even those enduring poor health outcomes. These positives are called assets and many are linked to protecting and promoting health.[26]



Assets exist at the individual, community and organizational level. Assets at the individual level are things like self-esteem, sense of purpose, and a commitment to learning. Assets at the community level are things like supportive networks, intergenerational solidarity, community cohesion, and religious tolerance. Assets at the organizational level are things like environments that promote physical, mental and social health, employment security, and safe and affordable housing.

Asset-based approaches to health proactively identify and fortify these assets as part of the treatment and management of conditions. This has the potential to improve health beyond the treatment and management alone.[26] While assets can be 'generic', understanding which assets are present and amenable to fortification in any specific community requires listening to its members, including service users.

Figure 2: The Importance of Listening



The Next Layer

Some disparities in health outcomes are due to unfair or unjust social arrangements. These 'arrangements' are codified in structures – the laws, regulations, policies, practices, resource flows, relationships, and norms that scaffold society, as well as the values and assumptions that underpin them.[27–31] When a disparity can be attributed to an unfair or unjust structure it is called an inequity.[32] Inequities in health, especially in the U.S., are patterned by racism.[27] Any focus on health inequity, then, must also contend with structural racism.

However, health systems have very little control over health. This is because health is 'determined' by the social conditions in which people are born, live, learn, work, play, worship, and age.[33,34] Some have estimated that health care's contribution to health is as low as 16%.[35] Our social conditions are 'determined' by numerous systems – political, economic, policing, housing, environmental, etc. The evidence suggests that all of these systems have unfair or unjust structures, including due to racism, and hence produce inequities.[36] The racism, then, is not just structural but systemic, and its impact is compounding.

No one can understand systemic unfairness or injustice, including systemic racism, better than the people experiencing it. While health systems might want to co-design health services, what they'll hear when they listen goes well beyond a condition and its treatment and management. This has the potential to change how people working in systems understand the world – i.e. their mental models. Changing the mental model of system leaders is known to be one of the most effective ways to change a system.[37,38]

The Deepest Layer

Many communities enduring poor health due to unfair or unjust structures and systems are aware of the unfairness and injustice. They experience it every day. As a consequence, and quite understandably, they do not trust the systems.

At the same time, many such communities have been 'engaged' over the decades, often quite inauthentically,[17] in initiatives that have sought to 'improve outcomes' or 'change the system'. While these initiatives may have led to some improvement or change, the fact that inequities persist — and are even worsening for some groups[39] — shows that these positives were small, short-lived, or both. This further deepens distrust.



The deepest value of listening, then, is building trust. Listening, alone, however, cannot do that — communities also need to see action and to feel the benefits — but it all starts with genuine listening. In essence, trust is born of *authentic* processes that *genuinely* seek to change systems and improve outcomes.

The Process of Listening

Listening to service users requires dedicated processes. Practice-based evidence yields two important insights for these processes. The first is that they involve intentionally 'making space' for service users to be heard.[31,40] The second is that paid caregivers, such as community health workers, promatores, and doulas, often have similar lived experiences as service users enduring inequities and can provide a critical link between them and the health system.[41,42]

Making space does not have to be physical. It could also be achieved by agreed collective practices for sharing experiences, formal agreements, or working groups acknowledging the knowledge of service users, co-decision-making processes, or co-governance arrangements.[40] At its core, making space is about creating an environment that humanizes the service design process so that trust is built between service users and people working in systems such that all participants are more likely to share and combine their expertise.



Paid caregivers work to improve overall health in under-resourced communities by providing social support, care coordination, navigation, coaching, and advocacy.[41] They can improve health equity by working at two levels: individual and institutional.

At the individual level, they can share lived experience, identify the assets that groups have, including how those assets might be fortified to protect and promote health, and advocate for and with service users to ensure access to resources.

At the institutional level, they often understand how systems work and can illustrate to leaders how their structures create and compound inequities, the idea being to change how they understand the world – i.e. their mental models.[7]

Co-design as a Bridge

Building on the above, co-design in health can be seen as a bridge between two crucial aspects of population health improvement – community power and system change.

Community Power

Community power is a much-abused term in health, but recent scholarship is bringing clarity.[20,43–46] A current definition is:

- The ability of people with similar experiences, identity, or purpose to develop, sustain, and grow an organized base of people who implement strategies and tactics through democratic structures to shift public discourse, set agendas, and influence those who make decisions in order to achieve collective goals.[47]

Communities build their power through the agency of individuals within those communities. Conversely, communities with power encourage individuals within them to use their agency.[19,48] Both individual agency and elements of community power are fostered through co-design processes. For instance, drawing from the text above:

- Individual agency is underpinned by things like self-esteem, skills, confidence, knowledge, capacity, and a sense of purpose.
- Establishing if people have similar experiences, identity, or purpose can happen through creating positive relationships between users, caregivers and professionals, as well as building social capital.
- Developing, sustaining, and growing an organized base of people is aided by strengthening networks and building community and social cohesion.
- And implementing strategies and tactics is aided by communities understanding how systems are organized.

All of these things contribute to the 'capacity' of a community, a multi-dimensional concept related to a community's ability to solve its problems encompassing participation, leadership, organizational structures, skills, resources, networks, access to third parties, and a sense of community.[49–51]

This capacity provides the conditions in which community power can grow and be more effectively wielded to bring about structural change.[52]



Systems Change

The importance of co-design in system change is perhaps already well-evident in the text above, but it's worth pulling out the different levels at which it operates:

1. Enhancing the performance, experience and value of a service;
2. Generating ideas beyond the immediate service for how the wider system can change;
3. Changing the mental models of people working in systems.

Our Commitment to Intentional Co-Design



Ultimately, co-design is a structure. It is a practice underpinned by the value that no one can understand systemic unfairness or injustice better than the people experiencing it. It creates the conditions for shared analysis, shared power, and making systems fairer and more just. If scaled, it has the potential to lead to the kind of co-governance of health that many advocates of social justice have called for.[53–55]

Given its importance and our 30 years of working with communities, community advocates, and system leaders in numerous types of projects, this paper codifies our Intentional Co-Design approach – an agile, community-centered approach to design that seeks to build trust with and between all stakeholders by: acknowledging that communities have essential expertise; ensuring community members have the capacity to participate effectively; and advocating that key decisions are made by community members.

In the following pages, we included a set of definitions critical to the understanding of Intentional Co-Design, in an effort to clarify and align on the terms used in this paper to describe it.

Intentional Co-Design is an evolving practice, not a finished framework. We welcome your feedback, suggestions, challenges, and additions as we continue to learn, refine our approach, and bring more people into the work of building healthier, more equitable systems together.

To learn more about how we tailor the core elements of Intentional Co-Design in our work across the U.S., reach out to info@heathleadsusa.org.

Acknowledgements

This paper reflects 30 years of learning alongside community members, caregivers, community-based organizations, health systems, and many other partners who have challenged our assumptions, shared their expertise, and helped shape how we work together to make our systems of health fairer and more just.

We offer special thanks to Pritpal S. Tamber and Health Leads team members for their intellectual partnership, thoughtful contributions, and commitment to advancing our understanding of community power, co-design, and co-governance. We are also deeply grateful to the many community partners whose experiences, insights, and leadership continue to inform and shape this work.

Definitions

To produce this white paper, we generated the below lexicon. We relied heavily on the peer-reviewed and indexed health literature. However, we acknowledge that that knowledge base is only partial and infused with racism. What follows, then, are current definitions that we are sure will evolve as a fuller, anti-racist knowledge base surfaces. With that in mind, we invite any and all feedback.

Accountable: People are able to ensure that both public and private actors with decision-making power in public health, health care, and community-based service provision are responsive to public needs and priorities, and are both answerable and subject to meaningful and enforceable legal, political, or economic sanctions if those needs and priorities are ignored.[53]

Agency: The ability to make decisions and act independently.

Assets: The collective resources which individuals and communities have at their disposal, which protect against negative health outcomes and promote health status.[26]

Barriers: The things preventing people from accessing the resources and opportunities required for health. Some barriers are structural and unjust, and give rise to inequities. Some such barriers have been in place since the founding of the country.

Belonging: A dynamic feeling and experience that emerges from whether individuals have the competencies, opportunities, and motivations to belong, as well as their experience of trying to belong, that arise from and are supported by the social system in which they reside.[56]

Caregiver: A person who provides assistance with another person's social or health needs, whether as a family member, formally or informally, or paid or unpaid, and who may or may not have formal training.[57] Often, caregivers share the same lived experience as the people they assist. They can operate both in institutions and in the community, the latter sometimes through community-based organisations.

Co-Design: An approach to design that attempts to involve a variety of stakeholders (e.g. employees, partners, customers, citizens, end users) in the design process to help ensure the result meets their needs and priorities, and is usable.[9,58]

Co-Governance: A collection of participatory models and practices in which governments, systems and communities share power by working together through formal and informal structures and relationships to make collective decisions, co-create programs to meet community needs and priorities, and ensure those policies and programs are implemented effectively.[55]

Community: A group of people with similar experiences, identity, or purpose

Community Capacity: A multi-dimensional concept related to a community's ability to solve its problems encompassing participation (both generally and in the health initiative), leadership (whether formal or informal, and supported by a strong base of actively involved residents), organizational structures (able to collect and represent the views of residents), skills (from the basics of participating and collaborating to being able to analyze issues), resources (such as money, mutual aid, social capital and communication channels), networks (whether of people or organizations), access to third party entities (that can act as an enabling intermediary between people and organizations in communities), technology (such as tools, systems, knowledge, and practices), and a sense of community (such as a connection to people and place and a concern for the issues affecting people).[49–52,59]

Community Engagement: Processes through which community members participate in solving problems and addressing concerns.[15,17,18,20,60]

Community Development: A way of working underpinned by a commitment to equity, social justice and participation that enables people to strengthen networks and identify common concerns and supports them in taking action related to them.[16]

Community-Led System Change: An intentional process in which people outside the targeted system attempt to alter the status quo by shifting and realigning the structures that uphold it through their ability to shift mindsets, set agendas, and influence or make decisions, as well as ensuring those decisions are implemented.[40]

Community Partners: Individuals and organizations that support communities by providing services or serving as a trusted voice.[47]

Community Power: The ability of people with similar experiences, identity, or purpose to develop, sustain, and grow an organized base of people who implement strategies and tactics through democratic structures to shift public discourse, set agendas, and influence those who make decisions in order to achieve collective goals.[47]

Control: The power to influence or direct people's behavior or the course of events.

Decision-Making: One of the three forms of power, the action or process of making decisions, especially important ones.[43]

Disparity: Differences in outcomes that are due to natural, biological variation, health-damaging behavior, and the transient health advantage of one group over another when that group is first to adopt a health-promoting behavior (as long as other groups have the means to catch up fairly soon).[32]

Equity: The quality of being fair and just.

Health Equity: A situation in which everyone has fair and just economic, political, and social opportunities to be healthy.[32]

Inequity: Differences in outcomes that are unnecessary and avoidable, and occur due to unfair and unjust social arrangements that are codified in the structures that uphold society.[28-30,32]

Inequality versus Inequity: In terms of health outcomes, both terms mean differences but whereas inequality is purely descriptive, inequity is normative – it embodies the idea that those differences are due to unfair or unjust social arrangements.

Innovation: Making changes in something established, especially by introducing new methods, ideas, or products. Classically, innovation can be incremental (or sustaining) or radical (or disruptive). Incremental innovation improves an established process, product or service without changing its fundamental structure (most quality improvement initiatives are this). Radical innovation creates a fundamentally new way of doing something, often displacing the established model entirely.

Institutional Racism: Structural racism (see definition below) that involves institutional systems and structures.[29]

Justice: Behavior or treatment that is considered morally right and fair and also formalised by being codified into law or other systems of the state.

Knowledge: What is known when data and information are interpreted, understood, and integrated by prior education and experience, including lived experience.[61]

Lived Experience: The knowledge acquired through first-hand involvement or exposure to particular events, occurrences or conditions.[25]

Power: The ability to bring about social, political, and economic change by shifting public discourse, setting agendas, and influencing those who make decisions.[43,,62]

Quality Improvement: The combined and unceasing efforts of everyone – healthcare professionals, patients and their families, researchers, payers, planners and educators – to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development.[29] Often synonymous with incremental innovation (see Innovation).

Racial Health Equity: A situation in which people who are part of a particular racial or ethnic group (or the social interpretation of which racial or ethnic group they are part of) have a fair and just opportunity to be healthy.

Racism: A system of structuring opportunity and assigning value based on whether a person or people are part of a particular racial or ethnic group (or the social interpretation of which racial or ethnic group that person or people are part of) that unfairly disadvantages some, unfairly advantages others, and saps the strength of the whole society through the waste of human resources.[64]

Resources: The things needed to be healthy, including not only medical care but also health-promoting living and working conditions.[65]

Sense of Coherence: A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that: the stimuli deriving from one's internal and external environments in the course of living are structured, predictable and explicable (ie comprehensible); the resources are available to one to meet the demands posed by these stimuli (ie manageable); and these demands are challenges worthy of investment and engagement (ie meaningful).[23,66,67]

Sense of Control: The ability of people to deal with the forces that affect their lives, even if they decide not to deal with them.[23,67,68]

Share Power: When different stakeholders, especially those within and outside formal systems, collectively shift public discourse, set agendas, and influence those who make decisions in order to achieve collective goals.

Social Determinants of Health: The conditions in the environments where people are born, live, learn, work, play, worship, and age.[34]

Stakeholder: A person, family member, caregiver, patient advocate, community member, community organization, institution or system with an interest or concern in something irrespective of whether they have the power to influence it.[69,70]

Structural Change: An intentional process designed to alter the status quo by shifting and realigning the laws, regulations, policies, practices, resource flows, relationships, and norms that uphold a targeted system, as well as the values and assumptions that underpin them.

Structural Determinants of Health: The laws, regulations, policies, practices, resource flows, relationships, and norms that shape the conditions in the environments where people are born, live, learn, work, play, worship, and age.[28-30]

Structural Racism: The totality of ways in which a society disadvantages some individuals and communities and advantages other individuals and communities through unfair and unjust structures, such as laws, regulations, policies, practices, resource flows, relationships, and norms, based on whether a person or people are part of a particular racial or ethnic group (or the social interpretation of which racial or ethnic group that person or people are part of). The process typically occurs through multiple institutions and systems, which is mutually reinforcing, and also reinforces discriminatory beliefs and values.[27, 29,30,64]

Structures: The laws, regulations, policies, practices, resource flows, relationships, and norms that uphold society, as well as the values and assumptions that underpin them.[28-31]

System Change: An intentional process designed to alter the status quo by shifting and realigning the form and function of a targeted system.[38]

Systemic: The involvement of whole systems, and often all systems – for example, political, legal, economic, health care, school, and criminal justice systems – including the structures that uphold the systems.[29]

Unfair versus Unjust: Unjust is used in more formal situations and carries connotations of a situation offending society's agreed moral codes and standards as set out in law or in the systems of state. Unfair is less formal and is an appeal to commonly held perceptions of what is decent and proper.

References

1. Onie R. *What If Our Health Care System Kept Us Healthy?* 2012. https://www.ted.com/talks/rebecca_onie_what_if_our_health_care_system_kept_us_healthy

2. Onie RD, Lavizzo-Mourey R, Lee TH, Marks JS, Perla RJ. Integrating Social Needs Into Health Care: A Twenty-Year Case Study Of Adaptation And Diffusion | Health Affairs Journal. *Health Aff (Millwood)*. 2018;37(2). doi:https://doi.org/10.1377/hlthaff.2017.1113

3. Taz Hussein, Collins M. The Community Cure for Health Care. *Stanf Soc Innov Rev*. Published online July 21, 2016. Accessed April 21, 2026. https://ssir.org/articles/entry/the_community_cure_for_health_care

4. Health Leads. *Changing What Counts As Healthcare: Grow & Catalyze Strategy 2014-2018*. Health Leads; 2019. https://healthleadsusa.org/wp-content/uploads/2019/02/Health-Leads-Grow-Catalyze-Strategy_February-1.pdf

5. Health Leads. *Building Healthy Communities - Health Leads 2019-2020 Impact Report*. Health Leads; 2021. https://healthleadsusa.org/wp-content/uploads/2021/09/HealthLeads_Annual-Report_2020_digital.pdf

6. Health Leads. *Building an Equitable Food System: For Boston Communities, By Boston Communities*. Health Leads; 2026. https://healthleadsusa.org/wp-content/uploads/2025/06/Neighborhood-Food-Action-Collaborative-Infographic.pdf

7. Health Leads. *Community Health Workers, Localized Data and The Path to Healthier Families*. Health Leads; 2026. https://healthleadsusa.org/wp-content/uploads/2019/03/NY-WIC-Case-Study-4319.pdf

8. International Organization for Standardization. ISO 9241-210:2019 - Ergonomics of human-system interaction (Part 210: Human-centred design for interactive systems). ISO. 2025. Accessed March 17, 2026. https://www.iso.org/standard/77520.html

9. Silvola S, Restelli U, Bonfanti M, Croce D. Co-Design as Enabling Factor for Patient-Centred Healthcare: A Bibliometric Literature Review. *Clin Outcomes Res*. 2023;15:333-347. doi:10.2147/CEOR.S403243

10. Thomas G, Lynch M, Spencer LH. A Systematic Review to Examine the Evidence in Developing Social Prescribing Interventions That Apply a Co-Productive, Co-Designed Approach to Improve Well-Being Outcomes in a Community Setting. *Int J Environ Res Public Health*. 2021;18(8):3896. doi:10.3390/ijerph18083896

11. Green T, Bonner A, Teleni L, et al. Use and reporting of experience-based codesign studies in the healthcare setting: a systematic review. *BMJ Qual Saf*. 2020;29(1):64-76. doi:10.1136/bmjqs-2019-009570

12. Pirinen A. The Barriers and Enablers of Co-design for Services. *Int J Dsign*. 2016;10(3). Accessed April 22, 2026. https://www.ijdesign.org/index.php/IJDesign/article/view/2575/750

13. Calancie L, Fair ML, Wills S, et al. Implementing a stakeholder-driven community diffusion-informed intervention to create healthier, more equitable systems: a community case study in Greenville County, South Carolina. *Front Public Health*. 2023;11. doi:10.3389/fpubh.2023.1034611

14. Estrada-Magbanua WM, Huang TTK, Lounsbury DW, et al. Application of group model building in implementation research: A systematic review of the public health and healthcare literature. *PLOS ONE*. 2023;18(8):e0284765. doi:10.1371/journal.pone.0284765

15. Popay J. Community Empowerment and Health Improvement: The English Experience. In: Morgan A, Davies M, Ziglio E, eds. *Health Assets in a Global Context: Theory, Methods, Action*. Springer; 2010:183-195. doi:10.1007/978-1-4419-5921-8_10

16. World Health Organization. *Community Participation in Local Health and Sustainable Development: Approaches and Techniques*. 2002. Accessed March 17, 2026. https://www.who.int/publications/i/item/9789289010849

17. Arnstein SR. A Ladder Of Citizen Participation. *J Am Inst Plann*. 1969;35(4):216-224. doi:10.1080/01944366908977225

18. IAP2. IAP2 Spectrum of Public Participation. Published online 2024. https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/iap2_spectrum_2024.pdf

19. Tamber PS. *The Bio-Medical Evidence Linking Community Agency and Health: An Encouraging Evidence Base*. Pritpal S Tamber Ltd; 2020. https://communityandhealth.info/publications/#the-bio-medical-evidence-linking-community-agency-and-health

20. Iton A, Ross RK, Tamber PS. Building Community Power To Dismantle Policy-Based Structural Inequity In Population Health. *Health Aff (Millwood)*. 2022;41(12):1763-1771. doi:10.1377/hlthaff.2022.00540

21. Pastor M, Speer P, Gupta J, Han H, Ito J. Community Power and Health Equity: Closing the Gap between Scholarship and Practice. *NAM Perspect*. Published online June 13, 2022. doi:10.31478/202206c

22. Antonovsky A. The salutogenic model as a theory to guide health promotion. *Health Promot Int*. 1996;11(1):11-18. doi:10.1093/heapro/11.1.11

23. Syme SL. Control and health: An epidemiological perspective. In: *Self-Directedness: Cause and Effects Throughout the Life Course*. 1st Edition. Psychology Press; 1990. https://psycnet.apa.org/record/1990-98544-012

24. Heller JC, Fleming PJ, Petteway RJ, Givens M, Pollack Porter KM. Power Up: A Call for Public Health to Recognize, Analyze, and Shift the Balance in Power Relations to Advance Health and Racial Equity. *Am J Public Health*. 2023;113(10):1079-1082. doi:10.2105/AJPH.2023.307380

25. Parsell C, Kuskoff E, Constantine S. What is the Scope and Contribution of Lived Experience in Social Work? A Scoping Review. *Br J Soc Work*. Published online July 4, 2024:bcae106. doi:10.1093/bjsw/bcae106

26. Glasgow Centre for Population Health. *Asset Based Approaches for Health Improvement - Redressing the Balance*. 2011.

27. Bailey ZD, Krieger N, Agénor M, Graves J, Linos N, Bassett MT. Structural racism and health inequities in the USA: evidence and interventions. *The Lancet*. 2017;389(10077):1453-1463. doi:10.1016/S0140-6736(17)30569-X

28. Solar O, Irwin A. *A Conceptual Framework for Action on the Social Determinants of Health*. WHO; 2010. Accessed January 5, 2025. https://www.who.int/publications/i/item/9789241500852

29. Braveman PA, Arkin E, Proctor D, Kauh T, Holm N. Systemic And Structural Racism: Definitions, Examples, Health Damages, And Approaches To Dismantling. *Health Aff (Millwood)*. 2022;41(2). doi:10.1377/hlthaff.2021.01394

30. Heller JC, Givens ML, Johnson SP, Kindig DA. Keeping It Political and Powerful: Defining the Structural Determinants of Health. *Milbank Q*. Published online February 16, 2024. doi:10.1111/1468-0009.12695

31. Farhang L, Gould S. Racial Justice and Power Sharing: The Heart of Leading Systems Change. In: *Leading Systems Change in Public Health: A Field Guide for Practitioners*. First. Springer Publishing; 2021. https://www.springerpub.com/leading-systems-change-in-public-health-9780826145086.html#productdetails

32. Whitehead M. The concepts and principles of equity and health. *Int J Health Serv Plan Adm Eval*. 1992;22(3):429-445. doi:10.2190/986L-LHQ6-2VTE-YRRN

33. Commission on Social Determinants of Health. Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health (Final Report of the Commission on Social Determinants of Health). Published online 2008:247.

34. Office of Disease Prevention and Health Promotion. Healthy People 2030. Healthy People 2030. 2025. Accessed February 21, 2025. https://odphp.health.gov/healthypeople

35. Hood CM, Gennuso KP, Swain GR, Catlin BB. County Health Rankings: Relationships Between Determinant Factors and Health Outcomes. *Am J Prev Med*. 2016;50(2):129-135. doi:10.1016/j.amepre.2015.08.024

36. Love B, Hayes-Greene D. *The Groundwater Approach: Building a Practical Understanding of Structural Racism*. Racial Equity Institute; 2018. https://racialequityinstitute.org/groundwater-approach/

37. Meadows D. Leverage Points: Places to Intervene in a System. The Academy for Systems Change. 1999. Accessed September 3, 2025. https://donellameadows.org/archives/leverage-points-places-to-intervene-in-a-system/

38. Foster-Fishman PG, Nowell B, Yang H. Putting the system back into systems change: a framework for understanding and changing organizational and community systems. *Am J Community Psychol*. 2007;39(3-4):197-215. doi:10.1007/s10464-007-9109-0

39. Health TLP. A missed opportunity to tackle health inequity in the USA? *Lancet Public Health*. 2024;9(8):e533. doi:10.1016/S2468-2667(24)00168-3

40. Carroll-Scott A, Grayam B, Tamber PS, Pagan S, Duhaney S, Iton AB. Defining Community-Led Systems Change: A Cross-Case Analysis of Community Power And Systems Transformation. *Submission Pending*.

41. Knowles M, Crowley AP, Vasan A, Kangovi S. Community Health Worker Integration with and Effectiveness in Health Care and Public Health in the United States. *Annu Rev Public Health*. 2023;44(Volume 44, 2023):363-381. doi:10.1146/annurev-publhealth-071521-031648

42. Abbi-Patel S, Sanchez-Cruz A. Assessing the Equitable Inclusion of Marginalized Workers (SSIR). *Stanf Soc Innov Rev*. Published online June 5, 2025. Accessed April 21, 2026. https://ssir.org/articles/entry/health-care-promoters-inclusion-assessment

43. Lukes S. *Power: A Radical View*. 1st ed. Bloomsbury Publishing; 1974. Accessed April 10, 2024. https://www.bloomsbury.com/uk/power-9781352012347/

44. Healy R, Hinson S. *The Three Faces of Power*. Grassroots Policy Project; 2013. https://grassrootspowerproject.org/analysis/the-three-faces-of-power/

45. Pastor M, Ito J, Wander M. *Leading Locally: A Community Power-Building Approach to Structural Change*. USC Dornsife Equity Research Institute; 2020. https://www.lead-local.org/findings

46. Heller JC, Little OM, Faust V, et al. Theory in Action: Public Health and Community Power Building for Health Equity. *J Public Health Manag Pract*. 2023;29(1):33. doi:10.1097/PHH.0000000000001681

47. Iton AB, Tamber PS, Barnett GM, et al. How Health Departments Can Use Inside-Outside Strategies to Build Partnerships With Community Power-Building Organizations to Achieve Structural Change. *Milbank Q*. 2026;104(1 (March 2026)):58-75. doi:10.1111/1468-0009.70068

48. Speer PW, Hughey J. Community organizing: An ecological route to empowerment and power. *Am J Community Psychol*. 1995;23(5):729-748. doi:10.1007/BF02506989

49. Goodman RM, Speers MA, Mcleroy K, et al. Identifying and Defining the Dimensions of Community Capacity to Provide a Basis for Measurement. *Health Educ Behav*. 1998;25(3):258-278. doi:10.1177/109019819802500303

50. Labonte R, Laverack G. Capacity building in health promotion, Part 1: For whom? And for what purpose? *Crit Public Health*. 2001;11(2):111-127. doi:10.1080/09581590110039838

51. Butterfoss FD, Kegler MC. Toward A Comprehensive Understanding Of Community Coalitions: Moving From Practice to Theory. In: *Emerging Theories In Health Promotion and Practice: Strategies for Improving Public Health*. 1st ed. Jossey-Bass/Wiley; 2002.

52. Kegler MC, Hermstad A, Bigger L, et al. A mixed methods analysis of community capacity to address health equity in the rural Southern U.S. *Int J Equity Health*. 2025;24(1):223. doi:10.1186/s12939-025-02589-x

53. Palmquist B. Equity, Participation, and Power: Achieving Health Justice Through Deep Democracy. *J Law Med Ethics*. 2020;48(3):393-410. doi:10.1177/1073110520958863

54. Ito J, Thomas AK, Pastor M. *Looking Around the Corner: (Re)Imaging Power for a Healthy and Just California*. USC Equity Research Institute; 2023. https://dornsife.usc.edu/eri/publications/looking-around-the-corner/

55. Palmquist B. *Assemblies As A Tool For Just Democracies*. Partners for Dignity & Rights; 2025. https://dignityandrights.org/resources/assemblies/

56. Allen KA, Kern ML, Rozek CS, McInerney DM, Slavich GM. Belonging: a review of conceptual issues, an integrative framework, and directions for future research. Aust J Psychol. 2021;73(1):87-102. doi:10.1080/00049530.2021.1883409

57. Centers for Disease Control and Prevention. Caregiving for Family and Friends – A Public Health Issue. February 13, 2019. doi:10.15620/cdc/85158

58. Wikipedia. Participatory design. In: Wikipedia. Wikimedia Foundation Inc.; 2026. Accessed April 14, 2026. https://en.wikipedia.org/w/index.php?title=Participatory_design&oldid=1344103919

59. Birgel V, Decker L, Röding D, Walter U. Community capacity for prevention and health promotion: a scoping review on underlying domains and assessment methods. Syst Rev. 2023;12(1):147. doi:10.1186/s13643-023-02314-1

60. Gonzalez R. The Spectrum of Community Engagement to Ownership. Published online 2019. Accessed July 22, 2024. https://movementstrategy.org/resources/the-spectrum-of-community-engagement-to-ownership/

61. Ackoff R. From data to wisdom. J Appl Syst Anal. 1989;16:3-9.

62. King, Jr. ML, Carson (Editor) C. The Autobiography of Martin Luther King, Jr. Warner Books; 1986.

63. Batalden PB, Davidoff F. What is "quality improvement" and how can it transform healthcare? BMJ Qual Saf. 2007;16(1):2-3. doi:10.1136/qshc.2006.022046

64. The Institute for Health Policy. How racism makes people sick: A conversation with Camara Phyllis Jones, MD, MPH, PhD. The Institute for Health Policy. August 2, 2016. Accessed February 21, 2025. https://www.kpihp.org/blog/how-racism-makes-people-sick-a-conversation-with-camara-phyllis-jones-md-mph-phd/

65. Braveman P. What are Health Disparities and Health Equity? We Need to Be Clear. Public Health Reports®. 2014;129(1_suppl2):5-8. doi:10.1177/00333549141291S203

66. Antonovsky A. Unraveling the Mystery of Health: How People Manage Stress and Stay Well. Jossey-Bass Publishers; 1987.

67. Marmot M. The Status Syndrome: How Social Standing Affects Our Health and Longevity. Bloomsbury; 2004.

68. Syme SL. Social Determinants of Health: The Community as an Empowered Partner. Prev Chronic Dis. 2004;1(1). doi:15634364

69. Agency for Healthcare Research & Quality. Patient-centeredness, Diversity, and Stakeholder Engagement. July 2023. Accessed June 22, 2026. https://www.ahrq.gov/pcor/strategic-framework/stakeholder-engagement.html

70. Kapiriri L, Donya Razavi S. Salient stakeholders: Using the salience stakeholder model to assess stakeholders' influence in healthcare priority setting. Health Policy OPEN. 2021;2:100048. doi:10.1016/j.hpopen.2021.100048

About Us

Health Leads is a national nonprofit advancing racial health equity by co-designing with caregivers and care workforces to ensure communities have the essential resources they need to thrive. With 30 years of experience working at the intersection of health care, public health and community, we believe better health is possible when communities are the designers and decision makers of the conditions shaping their health. Today, we're partnering with a range of organizations to build a care workforce in the U.S. that is valued, sustained, and shaped by the people it serves.

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