TOWARDS THE 'BELOVED COMMUNITY' Paper 8 in PSJP's Defining Key Concepts series

Philanthropy for Social Justice and Peace

About PSJP's Defining Key Concepts series

For philanthropy and development practices to have a significant impact on root causes of poverty, marginalization and violence, they need to be better aligned with social change agendas that are people led. This involves 'defining key concepts' that are commonly used in development and elucidating their meaning and implications in practice. PSJP has been facilitating a peer-learning environment in order to do this and has explored themes such as dignity, community resilience, measuring change, sustainability, community philanthropy, leadership, power, compassion among others.

The three papers that are included in this document and that were central to the discussions on compassion were written during the COVID crisis and so reflect some of the urgency about those times related to the pandemic. Nevertheless, the key messages that emerged are just as relevant for our current polycrisis.

These terms are frequently used in development and philanthropy, and they are included in many organizations' mission statements and performance indicators, but often there is no clear understanding of what they mean in practice or how they can be measured. As a first step to develop this understanding we have been facilitating discussions among a diverse set of practitioners in the field on these topics and producing papers that synthesize the discussions. These papers are available on http://www.psip.org. We hope to engage in wider ranging discussion in response to the papers and invite you to share your perspectives, experience and research on these themes.

About PSJP

Philanthropy for Social Justice and Peace (PSJP) is a programme whose purpose is to support the development and adoption of ideas about what makes a good society, to connect and strengthen the agents of this work and contribute to the infrastructure that supports progressive social change. PSJP is hosted by Global Dialogue, registered as a charity (1122052) and a limited company (05775827) in England and Wales.

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INTRODUCTION

The idea of 'development', classically framed since the Bretton Woods conference of 1944 and crystallised in President Truman's 1949 speech, has typically focussed on improving material progress, particularly for people experiencing poverty and excluded from the mainstream wealth creation processes. Success has typically been measured in economic terms, with the most common metric being per capita gross domestic product (GDP).

Despite immense economic progress since the Second World War, with per capita GDP rising almost everywhere and with absolute poverty much reduced, the world now faces an extended period of instability and insecurity resulting from a series of catastrophic events that have arisen, at least in part, because we have allowed economic growth to trump every other consideration while paying little attention to its distributional effects. GDP does not show the grossly unequal distribution of that wealth. So, while a few billionaires play in space, much of the world ekes out a minimum existence. In the process, we have ruined our environment, allowed a global pandemic to shut down the world, and allowed extremist rulers to close down civil society space and preach hate from positions of power. The domination of materialistic thinking has created this havoc, and we badly need an alternative to anchor us back to value-based living.

Now that our world is suffering from the consequences of the untrammelled pursuit of economic growth, we have little choice but to take an ecological approach or else we will make our planet unhabitable for human beings. It follows that we need to widen our horizons to get beyond the narrow confines of a material account of happiness to one in which we can flourish within the confines of the planet's ecosystem. In short, love must trump money. To accomplish this change, we need to move from a world based on competition to co-operation so economic growth is no longer the driving force, but that our feelings and relationships are our primary currency.

This means that it is now time to reform our understanding of good development. Long pursued by thoughtful civil society activists but barely recognised by official agencies, there is a strand of development that concentrates on human flourishing in its widest sense. Going way beyond 'homo economicus', it aims to fulfil the needs of people living in harmony with nature who possess an all-inclusive spirit of friendship and goodwill as an essential component of developing a good society for all its members.

A wonderful framing of the good society embodying these principles is the 'beloved community'. A term first coined by philosopher-theologian Josiah Royce (1855-1916) and popularized by Martin Luther King, Jr. (1929-1968), the beloved community describes a global vision of humans cooperating together in sharing the earth's abundance so that all people thrive. Recently, the animal protection and environmental movements have successfully made the case to broaden the scope of the beloved community to include animal

and all other life forms. These include both animate life forms such as trees, plants, insects, soil bacteria, and so forth, as well as to so-called "inanimate" life forms such as lakes, rivers, sky, soil, climate, mountains, and prairies.¹

People of the beloved community recognize the intrinsic worth of all people. Because members of the beloved community prioritize love, kindness, compassion, peace, and service, there is no place for hatred, envy, greed, or cruelty. Key actions involve removing societal ills such as homelessness, hunger, war, violence, poverty, and prejudice.

The way back to this all-inclusive oneness is by shedding our judgmental, greedy mental conditioning, and living from our inner boundless and unconditional love. Such a perspective is reflected in the teaching of all the world's main religions.

To accomplish the beloved community, requires what Joanna Macy has called 'the great turning'.² Her views echo those of Martin Luther King when he said:

'Our goal is to create a beloved community, and this will require a qualitative change in our souls as well as a quantitative change in our lives.'3

Joanna Macy points out that a precondition of the transformation will be by the 'great unravelling'. We are presently witnessing this as the polycrisis unfolds and continues. As one world dies; another is born.

So, what tools do we need for the great turning to take place? According to Joanna Macy, there are two key qualities we need – compassion and wisdom.

Compassion

In this paper as part of the PSJP series on 'Key Concepts in Development', we investigate one of these – compassion. Its importance lies in the fact that it forms the bridge between the human species and the beloved community.

The definition of compassion, according to the Merriam-Webster Dictionary, is the 'sympathetic consciousness of others' distress together with a desire to alleviate it'.

The Latin root for the word compassion is 'pati', which means 'to suffer', and the prefix 'com' means 'with'. So, compassion literally means 'to suffer with'. The connection of suffering with another person brings compassion beyond sympathy into the realm of empathy. However, compassion is much more than empathy.

³ Martin Luther King, Jr. from *Nonviolence: The only road to freedom*, May 4, 1966. Available from: https://www.gilderlehrman.org/sites/default/files/inline-pdfs/mlk_nonviolence_abridged.pdf

¹ <u>https://www.boundlessloveproject.org/news/2019/2/25/what-is-the-beloved-community-and-why-is-it-important</u>

² Macy, J. and Johnstone, C. (2022). Active Hope (revised). New World Library.

Action is the vital component that separates compassion from empathy, sympathy, pity, concern, condolence, sensitivity, tenderness, and commiseration. As the Bible puts it:

'Administer true justice; show mercy and compassion to one another. Do not oppress the widow or the fatherless, the foreigner or the poor. Do not plot evil against each other'.4

All the major religions of the world show the importance of treating our neighbour as ourselves. For example, Islamic traditions teach us the beauty in living a life caring for those around us.⁵

Link between compassion and the beloved community

In his final book *Where do we go from here: chaos or community?*, Martin Luther King made the connection between compassion and the beloved community:

'Let us be those creative dissenters who will call our beloved nation to a higher destiny. To a new plateau of compassion, to a more noble expression of humanness.'6

The Compassion Institute (California, USA) has a mission to advance compassion as a guiding principle and active force to foster a more caring world. Having reviewed the research, the Institute has found that compassion can obviously benefit those who are the recipients of compassionate actions, but also that compassion can have a wide range of psychological benefits for those who offer compassion to others. Moreover, compassion improves relationships, and assists in the development of a collective culture as opposed to an individual competitive one. Research has also shown that, although the capacity for compassion has evolved within the context of caregiving relationships, it is highly valuable in conflict situations, as it can prevent escalating tit-for-tat aggression." There is nothing new in these ideas. The ancient African philosophy of Ubuntu reminds us that 'I am what I am because of who we all are'.

Compassion is a key to the end of suffering. Yet it is rarely mentioned in the log-frame obsessed world of international development.

The aim and origins of this paper

This paper is based on two virtual sessions held in July 2021. There were three main presenters:

 Afsan Bhadelia PhD, Department of Global Health and Population, Harvard T.H. Chan School of Public Health, USA (As of

⁵ https://themuslimvibe.com/faith-islam/10-quranic-verses-and-hadith-on-how-to-treat-your-neighbor

⁴ Zechariah 7:9-10, New International Version

⁶ King, M.L (1967). Where do we go from here: chaos or community?, Beacon Press.

⁷ Condon, P. & DeSteno, D. (2011). <u>Compassion for one reduces punishment for another</u>. *Journal of Experimental Social Psychology, 47*, 698-701.

August 2022: Department of Public Health, College of Health and Human Science, Purdue University, USA);

- Leah Odle-Benson, The Stephen Lewis Foundation, Canada and;
- Stephen Connor PhD, Worldwide Hospice Palliative Care Alliance (WHPCA), USA.

For each of them, compassion is more than a human impulse, since their work lies at the intersection of care and justice and demands compassionate action. In July 2021, they came together with 34 other participants representing philanthropy and civil society to discuss the role of compassion in their work. The sessions were organised on the principle of 'Bohm Dialogue' creating a respectful, non-confrontational space, where we listen deeply in order to understand and co-create meaning in the process.

This paper offers slightly amended forms of their presentations from the dialogues and also draws on the ensuing discussion. It suggests that we need to put compassion towards the top of our agenda if we wish to alleviate individual and collective suffering. The paper is divided into four parts:

- 1. Understanding suffering
- 2. Strategies for building compassionate communities
- 3. Care and justice
- 4. The idea of compassion in development

Underpinning the whole of the paper is the question, can we build the 'beloved community' as the ultimate expression of the systemic transformations we seek in the world today?

The research and work of the three provocateurs and the dialogue process with the participants provide an understanding of the inequities of wealth, race, geography, and gender (among others) that underpin suffering, and of the ways of addressing avoidable suffering. It examines the values (through the palliative care framework) that foster compassionate communities and begins to shine the light on some of the elements of compassionate action in development and philanthropy through the work of the Stephen Lewis Foundation and other dialogue participants.

Words like compassion are not commonly discussed in the fields of philanthropy and development. It is therefore understandable that their true meaning and how it translates into strategic action is unclear. A colleague remarked at the start of one of our virtual sessions 'often in the kind of world that I've moved in - the human rights space, the community development space, the social justice space, we tend to be very task driven, and thinking about systems, which often take us into a kind of cold bureaucratic space, but I think today we're going to go into our basic humanity, and actually look at things from a different kind of perspective.' Other participants agreed, 'it's not

⁸ Martin Luther King popularised the notion of the 'beloved community', a 'truly brotherly society' as the ultimate expression of justice.

every day that you get invited to think about your work from the perspective of compassion and suffering, and it's a really useful reflection.'

By the end of the process, many people felt differently about the work of development. 'Systems are made up of people, and how do we make people transform systems through compassion?' remarked one participant while another shared, 'honestly, confessing myself the process of going through and preparing for this has been an eye-opener for me – I wouldn't have used the word compassion but actually I see now it's really central to how we are as people.'

Though some time has elapsed since these dialogues took place, we believe that their content is as pertinent as ever. The world is not short of crises. The need for compassion has seldom been greater or more urgent.

PART I: Alleviation of Suffering: Imperative of Justice and Solidarity⁹

Afsan Bhadelia, PhD

This section reviews the concept of suffering within the context of health and its alleviation through palliative care. Overall, it reviews how applying a framework of suffering at the individual, systems and societal levels is a matter of social justice and is critical to generating solidarity within the local and global beloved community. Specifically, it presents definitions of suffering overall and serious health-related suffering (SHS), as developed by the Lancet Commission on Global Access to Palliative Care and Pain Relief (henceforth referred to as the 'Lancet Commission') alongside its estimates on the global burden of SHS and opportunities to address it.¹⁰

In beginning to discuss the concept of suffering within the broader focus on fostering beloved communities, it is important to recognize the legacy of suffering due to myriad injustices that we have inherited and the need to account for it to promote solidarity. Suffering captures the distress, discomfort, and despair that individuals may experience due to, but not limited to, physical, psychological, social, and spiritual causes. Suffering can be unpacked in various ways. For example, it can be viewed from a subjective or an objective standpoint. The subjective pertains to experience, whether it be based on sensory, emotional, psychophysical, ontological, or existential stimuli. The objective component concerns the biological phenomenon that is observable and measurable. ^{11,12} There are other frameworks such as classifying suffering into 'elements', considering the 'essence of suffering', 'manifestation of suffering', and the 'cause of suffering' which may threaten the integrity of the person experiencing it. ¹³ These are all useful reference points when focusing on health.

The Lancet Commission presented serious health-related suffering (SHS) as a multidimensional concept with physical (e.g., pain), psychological (e.g., depression), social (e.g., stigma and discrimination), and spiritual (e.g., existential) that can be ameliorated with adequate access to palliative care. The purpose of quantifying SHS was to determine the extent of the problem, identify solutions and raise awareness to effectively address avoidable

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⁹ This section, as cited, is largely premised on collective work conducted by the Lancet Commission on Palliative Care and Pain Relief and is supplemented by the author's perspective.

¹⁰ Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, et al; Lancet Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. Lancet 2018; 7;391(10128):1391-1454.

¹¹ Bueno-Gómez N. Conceptualizing suffering and pain. Philos Ethics Humanit Med 2017; 12(1):7.

¹² Dekkers W. Pain as a subjective and objective phenomenon. In T. Schramme and S. Edwards (Eds.), Handbook of the Philosophy of Medicine, pp. 169–187. New York: Springer, 2017.

¹³ Kioko PM, Requena Meana P. The nature of suffering and its relief: a proposal for a redefinition. BMJ Support Palliat Care 2020; 10(1): e1.

¹⁴ Knaul et al 2018

suffering. Specifically, the Lancet Commission noted that "suffering is health-related when it is associated with illness or injury of any kind. Suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social or emotional functioning...Palliative care should be focused on relieving the SHS that is associated with life-limiting or life-threatening conditions or the end of life." The Lancet Commission then used this conceptualization to establish parameters for measurement.

The Lancet Commission measured suffering associated with 20 conditions and 15 physical and psychological symptoms most requiring palliative care. ¹⁶ In doing so, it identified one of the greatest global health inequities – of the more than 61 million people estimated to have either lived with or died while experiencing SHS in 2015, more than 80% were in in low- and middle-income countries (LMICs) where access to palliative care is either limited or non-existent. ^{17,18} This inequity was further affirmed by estimates that the poorest 50% of the world can only access 1% of opioids available for medical use while the richest 10% can access nearly 90% of them. ¹⁹ It should be noted that these figures are likely to be underestimates since they do not capture the social and spiritual dimensions of suffering due to data limitations. The ongoing work of the Lancet Commission seeks to expand and strengthen its estimates in terms of dimensions covered, conditions and symptoms included as well as to undertake examination of the needs of specific populations, including children.

The massive inequity in access to palliative care has largely gone unnoticed and not been prioritized for various reasons, including the lack of metrics related to suffering and the predominant policy and implementation focus on prolonging life and increasing productivity. However, through its work, the Lancet Commission not only exposed the extreme inequity but developed solutions to address it. The Lancet Commission designed an essential package of palliative care services that is low-cost because it includes non-patented medicines, frugal innovation in terms of equipment, is based on competency-based human resources, and can be delivered at the primary care level. The estimated cost is \$3 per capita or less that 3% of the overall cost of the essential universal healthcare coverage package calculated by the Disease Control Priorities Project, which is a global effort to quantify and cost different components of a broader package of health interventions that should

15 Knaul et al 2018

¹⁶ Knaul et al 2018

¹⁷ Knaul et al 2018

¹⁸ As of May 2024, the SHS 2.0 methodology has been developed to refine estimates of the need for palliative care globally and as documented in the following publication with updated SHS figures forthcoming: Kwete XJ[†], Bhadelia A[†], Arreola-Ornelas H, Mendez O, Rosa WE, Connor S, Downing J, Jamison D, Watkins D, Calderon R, Cleary J, Friedman JR, De Lima L, Ntizimira C, Pastrana T, Pérez-Cruz PE, Spence D, Rajagopal MR, Vargas Enciso V, Krakauer EL, Radbruch L[‡], Knaul FM[‡]. Global Assessment of Palliative Care Need: Serious Health-Related Suffering Measurement Methodology. J Pain Symptom Manage. 2024 Apr 16:S0885-3924(24)00708-5. († Joint first authors; [‡] Joint last authors).

¹⁹ Knaul et al 2018

²⁰ Knaul et al 2018

be available to all.21

The need to address avoidable suffering has only been amplified by the COVID-19 pandemic. Indeed, the pandemic has generated a 'tsunami of suffering'²² caused by the immense loss of life, of loved ones, of livelihoods and of justice. Marginalised communities have been disproportionately affected by the pandemic due to existing social and structural determinants of health inequities, including limited or no access to palliative care and pain relief. This is particularly the case in low-resource settings where health systems are weaker, there is less preparedness (e.g., lack of access to personal protective equipment), and limited training for basic palliative care.²³

Alleviation of SHS is of importance at various levels. At the individual level, it is important as a human right, and as a valued health goal of patients and caregivers given its relevance to improving their quality of life. At the systems level, it is a primary aim of medicine in general and of healthcare and health systems, and is the duty of healthcare providers in terms of providing compassionate care and promoting dignity in life and death throughout all aspects of healthcare delivery. At the societal level, it is a social justice issue at its core and from different perspectives of equity, such as gender. For example, women bear a disproportionate burden of caregiving responsibilities, including of individuals who are sick, and this has worsened during the pandemic.²⁴ Access to palliative care can be gender-transformative by aiding patients and caregivers alike, affording them professional caregiving to address their needs. Moreover, at the societal level, prioritizing suffering and applying the framework of suffering can help recognition of and response to the collective suffering resulting from the present pandemic as well as providing a view to examine beyond self and society to address planetary suffering. Brought together, the alleviation of suffering can be a part of building better futures for all and can generate solidarity through a collective sense of hope.

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²¹ Knaul et al 2018

²² Radbruch L, Knaul FM, de Lima L, de Joncheere C, Bhadelia A. The key role of palliative care in response to the COVID-19 tsunami of suffering. Lancet 2020; 395(10235):1467-1469. ²³ Radbruch et al 2020

²⁴ UN Women. COVID-19 and the care economy: immediate action and structural transformation for a gender-responsive recovery. Policy Brief No. 16. Accessible at: https://www.unwomen.org/-

[/]media/headquarters/attachments/sections/library/publications/2020/policy-brief-covid-19-and-the-care-economy-en.pdf?la=en&vs=407

PART II: Building Compassionate Communities

Stephen Connor

In this section we will explore the convergence of hospice palliative care, compassionate communities, and decent care values. For many, the term palliative care may be unfamiliar, often linked with hospice care and frequently avoided due to a perceived association with death and dying. While it is true that people living with palliative care needs have serious illness or impairments and eventually die, as do all of us, it is how we live well until we die that matters. The term palliative care refers to a philosophy of care that is focussed on relieving serious health-related suffering and improving quality of life. Hospice is generally referred to as a type of palliative care that focuses on delivering care near the end of life in multiple settings including personal residences, long-term care facilities, assisted living, hospitals, and purposebuilt inpatient facilities.

Palliative care has emerged over the past fifty plus years as a new specialization in healthcare that is considered an essential component of every healthcare system and a part of the continuum of universal healthcare (promotion, prevention, treatment, rehabilitation and palliative care). The philosophy behind it is mainly grounded in humanism and existentialism and requires that people with palliative care needs are treated compassionately as whole persons with a universal focus on physical, psychological, social, spiritual and practical needs. Care is interdisciplinary typically including nursing, medicine, social work, chaplaincy and volunteers. By interdisciplinary we mean not hierarchically organized but person-centred where the patients and families are at the centre of care and their goals drive the way care is delivered.



Figure 1: WHO Conceptual Model of Palliative Care Development

The development of palliative care follows a public health model developed originally by the World Health Organization that includes four components (policy, education, medicine availability and implementation). This model was recently updated to add research and empowered communities (see figure 1). Each of these components is essential for the development of palliative care in any country.

While palliative care must be integrated into existing health care systems it should also be owned by the communities where it is practised. This then brings us to the concept of compassionate communities. The compassionate community and palliative care movements are naturally aligned to deliver more than healthcare. Ideally the community compassionately supports those in their midst that have serious advanced illness and need palliative care. Volunteers can serve as a bridge between the community and families caring for their seriously ill loved ones in concert with health professionals with the knowledge and skills to manage preventable suffering.

Compassion and empathy are central to the palliative care philosophy. Compassionate communities don't always exist spontaneously and can be nurtured. Compassionate people live in a community system where compassionate relationships exist and where compassionate organizations and institutions together form a compassionate community as depicted in Figure 2.

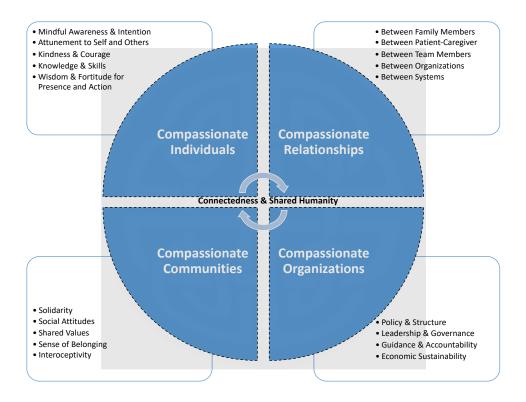


Figure 2: Model of Compassionate Community Development

We can see from this model that the development of compassionate communities begins with the nurturing of compassionate individuals and relationships through characteristics such as mindfulness, kindness, courage and wisdom in relationships between family members, caregivers, team members and systems. All this happens through a system where there is shared humanity and a sense of connectedness. Compassionate organizations require the support of leadership and a structure that embeds expectations into policy and where there is a competent commitment to financial stability. All this (people, relationships, organizations) is necessary to ultimately reach the wholeness of a compassionate community.

Many communities globally are beginning to make a commitment to achieving the status of compassionate community and, in these circumstances, caring for those with serious illness becomes much more feasible. One might be tempted to think that this can only happen in a high-income country setting, however, the emergence of compassionate communities is not tied strictly to available financial resources. Human resources are just as important and in resource-limited settings, it is not unusual for there to be more generosity and sharing than in many high-resource settings.

As an example, my organization (Worldwide Hospice Palliative Care Alliance) has helped with the vision and ownership of local champions, to support two such communities in Bangladesh. The first is a programme called 'Compassionate Korail', a community-based palliative care service in a major 'informal settlement' in Dhaka. The programme is supported by an anonymous UK Trust and was implemented by the Centre for Palliative Care at the main medical university in Dhaka. Palliative care assistants (PCAs) and volunteers cared for over 300 patients in the pilot backed up by nurses, physicians and therapists. At the end of the project, a local 'palliative care society' stepped in to continue the project. All the PCAs were young local people we trained in palliative care and over a thousand residents attended sensitivity training.²⁵ The community embraced the programme and couldn't imagine it not continuing. A second 'Compassionate Narayangani' project is still underway in a nearby city to Dhaka. 26

There are many values associated with palliative care in addition to empathy and compassion. The World Health Organization and the Altarum Institute in Washington DC created a project called Decent Care Values in Palliative Care for whom I was a co-investigator. The idea of Decent Care came out of the notion of Decent Work and was applied to the HIV pandemic where many people living with HIV and AIDS were not getting 'decent care' and faced severe discrimination, which is still happening today. To define 'Decent Care',

²⁵ Chowdhury MK, Ahmad N, Biswas F, Farheen N, Ferdous L, Maksoda D. Connor, S. (2021). Programme Evaluation: Improving the quality of life of older people in an urban slum in Bangladesh. Palliative Care and Social Practice, 15:1-10. DOI: 10.1177/26323524211063217

²⁶ Mostofa Kamal Chowdhury, Shafiquejjaman Saikot, Nadia Farheen, Nezamuddin Ahmad, Sarwar Alam, Stephen R Connor (2023) Impact of Community Palliative Care on Quality of Life among CancerPatients in Bangladesh. Int. J. Environ. Res. Public Health 2023, 20(15):6443

a set of values were identified that were operational at three levels (individual, social and systemic). The individual values were Agency and Dignity, the social values were Interdependence and Solidarity, while the systemic values were Subsidiarity and Sustainability. We recognize Agency as a stronger value than just autonomy though they are related. Subsidiarity simply means making decisions as much as possible at the local level.



From this review of the palliative care system, we can take away several insights. Healthcare systems need to ensure that compassion is a core component of all three of these levels and that palliative care is perhaps the best model of care delivery for today's healthcare system. We have a healthcare system that is funded for and spends 80% of resources on acute care, whereas 80% of the care needed today is for serious chronic conditions that eventually become life-limiting. Building compassionate organizations and communities starts with nurturing compassion in individuals and relationships. We have a long way to go to achieve this vision, but our future depends on it, and we need now to create the conditions for how we want to be cared for as we age and eventually die with compassion and dignity.

PART III: Living with Dignity; Relationships and Home-Based Care²⁷

Leah Odle-Benson

The widespread increase in access to Antiretroviral Therapy (ART) over the past decade is the great success story of the global HIV and AIDS response. It is by no means a cure, but it has radically transformed the landscape of the pandemic in sub-Saharan Africa, and it changed the primary challenge for community-based organizations from caring for the terminally ill to helping HIV-positive people maintain their health and well-being.

As access to ART increased, community-based organizations found that their home-based care programmes were as important as ever. Major funding for treatment went as far as getting ARVs into government-sponsored health facilities, yet people living in rural areas still experienced tremendous, often insurmountable, difficulty accessing medication. Significant support was still required to manage the myriad psychological and practical challenges involved in coming to terms with an HIV-positive diagnosis and successfully initiating and maintaining treatment over time. In response, many of the Stephen Lewis Foundation's (SLF) community-based partner organizations stepped in to fill the gap between medication and adherence.

Home-based care (HBC) is a vital part of the response to the HIV and AIDS pandemic in sub-Saharan Africa. Since 2005, SLF has supported grassroots, community-based organizations (CBOs) in their work to turn the tide of HIV and AIDS using HBC models as a primary care and support method. Today, the SLF partners with more than 125 organizations across 15 sub-Saharan African countries, many of which continue providing critical HBC to community members. Sub-Saharan Africa is home to 67% of all people living with HIV worldwide²⁸, but has just 3% of the global health workforce. In 10 of the 15 countries where the SLF works, there is only one doctor for every 10,000 people. In rural communities with limited traditional healthcare infrastructure and/or cost-prohibitive transportation, home-based care workers can reach marginalized and geographically isolated community members who would otherwise be missed by centralized healthcare systems. Where national health systems fail to reach people, community-based organizations (CBOs) are filling the gaps and consistently serving their communities.

Home-based care (HBC) was developed out of necessity as a response to the health needs of communities throughout sub-Saharan Africa. It reflects the idea that health services must reach people both where they are physically located and feel safe — their homes and local communities — and where they are emotionally, socially and mentally. By delivering healthcare in a client's home, HBC workers eliminate transportation barriers, reduce the impact stigma can have on decreasing a person's willingness to access services and

²⁷ Excerpt from the SLF's Healing Health and Hope; A Case for Support for Prioritizing Home-Based Care and Community-Based Responses to HIV and AIDS ²⁸ UNAIDS, <u>Fact Sheet – 2021</u>, p.2.

increase the safety and comfort a client feels in opening up and sharing their struggles. It includes a wide variety of primary health services for individuals at every stage of the life cycle, including, but not limited to, pre- and postpartum care, routine vaccinations, health education, management of common illnesses and follow-up of discharged patients. Depending on the country and context, home-based care is delivered by healthcare professionals, such as midwives and nurses, or by trained volunteers. A number of different terms are used to refer to home-based care workers, including Village Health Team (VHT) Worker, Community Health Worker (CHW), or Community Health Extension Worker (CHEW).

Home-based care workers – overwhelmingly women, mostly volunteers, many HIV-positive themselves – visit countless homes each day, travelling great distances, most often on foot or by bicycle. They dispense drugs and food and provide peer support and counselling. They bathe their clients and carry out household chores. They ensure that the children's needs are being met and identify families that are struggling and need more support. They provide palliative care for those in the last stages of AIDS. Above all, they provide a vital service by delivering healing, health and hope to the individuals and families in their care. Additionally, of the more than 5,000 home-based carers that our partners work with, approximately **70%** are female.²⁹ The path towards becoming an HBC worker usually starts with being an active recipient of support from the community-based organization, such as belonging to a mutual support group for people living with HIV (PLWH) or participating in an income-generating or savings and loans project. As their own lives stabilize, and their connection to the organization strengthens, these former beneficiaries start looking for ways to support their neighbours.

Home-based care is the backbone of the community response to HIV. HBC has always been and continues to be instrumental in increasing HIV testing, combatting gender-based violence, ensuring that orphaned and vulnerable children have holistic support and rebuilding communities devastated by the HIV pandemic. HBC programmes address the stigma, psychosocial realities, and discriminatory health access practices that continue to prevent or deter people from getting tested for HIV or adhering to treatment. In this way, home-based care treats the whole person through human connection and care by addressing social, economic and medical barriers to testing and treatment for HIV and AIDS.

However, the real transformative power of home-based care extends beyond these practical considerations. It comes from human connection. HBC workers forge close relationships with their clients that are built on trust and are responsive to the clients' diverse and individual needs. They attend holistically to the needs of entire families and rebuild the resilience of individuals and communities. In addition, HBC workers connect their clients

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matter the organization's size.

²⁹ There is significant variation from organization to organization in number of home-based caregivers they have. Our larger partners often report hundreds of HBC providers, while small organizations may report fewer than 10. What is constant is the gender differential, with women being much more likely to be the ones providing home-based care than men, no

with other support available from community-based organizations and, increasingly, with formal healthcare centres. Through home-based care, community-based organizations are able to effectively join forces with the formal health system so their clients receive the best possible care to thrive.

More than anything else, it's the human touch and personal connectedness that makes home-based care so remarkably effective. The carers build relationships of trust that allow families to feel comfortable talking about their experiences. The consistency of always connecting with one carer is tremendously important because it means that the family does not have to continuously disclose their issues to several people. Over time, as one home-based carer explained, "you become a friend" and confidant.

Home based care specifically:

- Combats Stigma & Discrimination Communities that have historically been excluded, including people living with HIV, LGBTIQ peoples, sex workers, and ethnic and linguistic minorities, are generally very poorly served by mainstream healthcare facilities and their members often encounter a great deal of discrimination from government staff. Home-based care delivered by members of the community provides much more welcoming and inclusive support.
- 2. **Provided Links to Community-Based Services -** HBC is also a vital entry point for direct assistance. One of the most important contributions made by HBC workers is the way in which they connect people to the other forms of support available.
- 3. **Supports Partnering with Local Government -** The widespread availability of ARVs has brought about a significant improvement in the interaction between community-based caregivers and government-sponsored health providers.

In addition to the challenges of HIV and AIDS, the ongoing global COVID-19 pandemic poses an additional major public health threat throughout the African continent, putting immense pressure on already overstretched and under-resourced health systems. With increased lockdowns or restrictions in many countries, access to food and medicine continues to be limited, and underfunded health systems remain under strain. At the time of this presentation, many of the SLF's partners are experiencing a difficult third wave of the pandemic amidst vaccine shortages. The Africa Centre for Disease Control and Prevention aims to vaccinate 60% of the African continent by the end of 2022, which is more than a year-and-a-half after similar targets in many other parts of the world. The COVID-19 pandemic in Africa, therefore, does not have an end in near sight.

Community-based organizations delivering home-based care provide a lifeline to people affected by HIV and AIDS because of their tangible connection to evolving community needs. We hope this presentation makes clear that the CBOs have not only figured out a key part of the HIV and AIDS puzzle, but that the solution they have found is dependent on the compassionate role that CBOs themselves play in and for their own communities. The community-based response cannot be mechanically applied by anyone, anywhere.

There's a real magic in how it works and this is the magic of the local people who 'have home-based care in our veins'. The human connectedness that CBOs can uniquely mobilize is a critical piece of this work.

Part IV: The Idea of Compassion in Development

This section is a synthesis of the discussions with the 34 participants of the virtual dialogue sessions.

Participants were invited to consider how the concept of compassion featured in their own work. The universal answer was that it was a central component of what they do and why they do it. While they all worked on alleviating human suffering there was a rich diversity in their approaches and day-to-day actions. Some worked at the individual level such as providing support to Alzheimer patients and their caretakers. There was a meditation community in the dialogue, as well as community-based, national or even international civil society organisations, activists and researchers who worked with marginalised or vulnerable populations within a justice and rights framework or on other socially or politically sensitive issues. In the end, the unifying understanding that emerged is that 'compassion' in development and philanthropy is not any single action, but the recognition of our shared humanity and interconnectedness; an understanding of the immanence of our inner worlds and their projection into the outer world; and it is a lens through which development and philanthropic practice is directed so that it is not just about alleviating individual suffering but enabling people, communities and the planet to thrive and flourish.

Compassion is action

A common interpretation of compassion is to feel *with* another person and to take action to reduce their suffering. In the widespread systemic injustices and social issues that many of the participants in our sessions deal with, in their day-to-day work, this emphasis on *action* as the ultimate expression of compassion was ubiquitous. A participant from a community-based fund working on post conflict issues in Eastern Europe shared,

'When it comes to our understanding of compassion, it's layered, it's really a lot of things, but it's actually nothing without supportive and constructive actions. Even if these actions are something simple like active listening, and tapping on someone's shoulder, whatever is necessary in the moment, but action is the key to compassion.'

In the Northeast of India another community philanthropy organisation said something similar.

'Compassion is when I put aside all constraints, take responsibility, go out and start working with the community to reduce their suffering. Compassion is actually putting the responsibility and ownership into actions, despite the limitations you or other organisations may have. It is very central to our work.'

Elements of compassionate practice in development

The dialogue participants stressed certain principles in their work that help imbue it with compassion. A colleague from a meditation community

distinguished between 'the impulse to do what we can to relieve suffering in any and all ways; and then the expression of that, is what we call skilful means, in other words how we pull it off.' That is to say, the true manifestation of compassionate action lies not in the 'what' of development work but in the 'how'.

Compassion is from the inside out

Many of the participants emphasised the palliative care model of Compassionate Community Development's premise that compassionate communities begin with the nurturing of compassionate individuals. 'The starting point for change at any level is not from the outside but it's from the inside.' For some participants, as changemakers, compassion for the self has become a priority need particularly in light of the shocks and demands of the COVID pandemic. The Executive Director of a charity that serves young people and children in Colombia shared how compassion for the self in difficult times has been the driving force that has kept her work going.

We now live with our biggest workload - being at home, taking care of our family, and continuing working, trying to keep our charities alive with all this risk. So, it's to continue serving the people that we have been serving for many years but also being compassionate with our colleagues, and with ourselves too, to not be so hard on ourselves.

Some of the participants also worked on creating conditions for compassion to be practised individually. A meditation community focused on human flourishing and overall well-being bases its work on three pillars of 'awareness, compassion and wisdom' and helps people develop or strengthen their own sense of compassion for themselves. They reinforced the framework of interconnectedness between individuals, relationships, organisations and communities, but noted that the individual is the starting point.

If any one of us is responding with compassion and loving kindness to the world around us it has a ripple effect that impacts others or can impact others in a positive way. So, I think that's the essence really of what we're trying to offer, is to really seed that motivation and provide tools for people to build those skills for themselves.

Compassion is in enabling and respecting agency

However, the dialogues also reflected that it is not enough for individuals to cultivate their own capacities for compassion, but that development and philanthropic action must enable environments that allow the capacity in the communities they serve to exercise control over decisions and actions that affect their lives, in other words, local 'agency'. Agency is also stressed in the decent care framework shared by Dr Stephen Connor. 'Decent Care Values directly address the disadvantage of marginalization at the individual level by asserting the rights and power of the individual to identify her or his own needs (agency and dignity).'30

³⁰ https://altarum.org/sites/default/files/uploaded-related-files/Decent%20Care%20Demo%20Final%20Report%202012%20-%20Altarum.pdf

A participant from a London-based NGO working with remote and marginalized communities in South Asia and East Africa confirmed this.

Compassion for us means a wish to relieve suffering, but also a wish to empower and to see people feel fulfilled. So, we look to enable choice among communities that have been left behind in the development process and are struggling to maintain agency and self-determination. So, I'd say for us compassion really drives our desire to do as much as we can to understand local aspirations and respect local cultures and habitats when delivering our programmes.

In similar vein, for a peacebuilder in Northern Ireland, compassion means having a 'listening ear', 'doing more listening than talking' and 'trying to amplify the voice of community'.

The value of interventions that enable and support 'agency' rather than undermine it through top-down decision-making processes and interventions is essential to lasting change and building resilient communities. A researcher working on disaster preparedness and resilience in Southeast Asia drew the association between agency as an expression of individual wellbeing and disaster resilience, 'there's a really strong association between a sense of agency, sort of independence and control of one's own destiny and future, and proclivity to prepare for disasters.'

Compassionate development is community-based

The three presenters emphasised that the expression of compassion has to come from within the communities in question. The Stephen Lewis Foundation, in its support of home-based care in the context of HIV and AIDS underscored the compassionate role that CBOs play in and for their own communities

The human connectedness that CBOs can uniquely mobilize is a critical piece of this work.

This stress on 'connectedness', presence and capacity to lend a listening ear as being critical to compassionate development practice is shared by other dialogue participants. According to a CBO in Romania, compassion is about 'respect, dignity, the capacity to hear others, to hear all the voices in the community, to give help.' One participant has built a small non-profit organisation in Mongolia to target malnutrition in the country. She, too, stresses the importance of community roots as the starting point of compassionate action.

I think it's very important if you are familiar with the culture, if you are originally from the place, if you speak the language, share the same culture, if your loved one or cared one lives in the country or in the place, that's where compassion starts. And it's very easy to understand and to try and come up with some kind of action.

This supports the conclusion drawn by Leah Odle-Benson above that 'community-based response cannot be mechanically applied by anyone, anywhere. There's a real magic in how it works and this is the magic of the local people who "have home-based care in our veins".

Compassionate development is based on solidarity

Another related feature of compassionate action in development is that it is founded in solidarity. A colleague from the meditation community in the discussions distinguished between compassion that is based on the understanding that we are the same, and compassion that might be based on a sense of 'I'm better than you, so I need to help you'.

For an organisation working with communities in various countries across Africa and South East Asia on sexual and reproductive health and rights, compassion and building a sense of solidarity is the starting point for change.

When people with experiences related to sexual violence, gender-based violence, human trafficking, sexual exploitation have come together and have shared those experiences for the first time, a common experience that we see in the first workshops that we hold, where after those workshops participants will come up to us and say 'Wow, I didn't realize until now, that actually there are other people in my community that have experienced the same things as I have.' It's really powerful, to have discovered for the first time that you are not alone, and that actually this has happened to other people. Connection is extraordinarily important in this process of change, it's about building solidarity, on the basis of shared experience. And I think the fact that people are able to discover their own voices and discover the value and importance of their experiences in our work is an expression of a very deep kind of compassion.

This connection is part of the therapeutic healing process of the group, whose members eventually go on to share their stories with a wider audience through an interactive theatre or radio format.

The goal of any kind of performance, whether it's on radio or in a community, is to enable the audience to experience compassion for the protagonist who again has often faced similar challenges that the audience has faced. And that's where the whole power of the approach comes from, the fact that as an audience member or listener you're hearing a story that resonates with your own story, your own experience in life, and that sense of compassion, of empathy, of connection is created. So when the time comes to invite the audience into the story to change the story for the better, they're ready to do that because that compassion and that connection is already there.

The researcher on disaster resilience drew attention to the Filipino concept of *Bayanihan* as an expression of compassion. *Bayanihan*³¹ refers to helping

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³¹ Historically *Bayanihan* has been a form of community assistance, how Fillipinos have

one another as a community. In a society that is dramatically affected by typhoons and other disasters, 'Bayanihan' is depicted in Filipino art as people picking up houses as a community and moving them out of harm's way. His research has also shown 'that people who are already engaged in social institutions, in community organisations, are also far more likely to prepare for disaster.'

Solidarity also underpins the work of a Dalit human rights activist in India. The Dalit community has suffered caste-based discrimination in India: 'for many thousands of years Dalit have been "guarantined" from society'. The foundation represented by the activist works on building connectedness and compassion for each other to mobilize the community to assert their rights and raise their voice for justice. 'I think compassion has created more power.'

Addressing the long-term conditions shaping suffering

As part of Asfan Bhadelia's presentation she reminded all:

As we convene today to discuss suffering and the fostering of beloved communities, we must face a legacy we have inherited and seek to change. There's a legacy of suffering due to systemic racism, sexism, settler-colonialism, alongside classism, ableism, ageism, and so much more. This is part of a long arc of suffering that we need to take account of and includes acknowledgement of the places, spaces. processes and actions that have brought us to this very point in time. Indeed, it is in my view essential to understanding justice and promoting solidarity. As such I acknowledge and recognise the grounds that I occupy and am presenting from today, as stolen lands that were historically the ancestral home of indigenous communities that were forcibly displaced, specifically I acknowledge the land beneath my feet at this very moment as unceded territory of the Yamassee tribe. I also acknowledge that the city from which I currently speak (Buford, South Carolina), was built by the Gullah-Geechee people who were enslaved by European colonisation. The minoritised communities I have mentioned are among those disproportionately experiencing various forms of avoidable suffering including serious health-related suffering which I will speak to more over my presentation.

While participants emphasized the importance of inner, personal and relational/social aspects of compassionate action in development and philanthropic practice, and in fact confirmed that the individual is the essential building block of the 'beloved community.' They recognised, in tune with Dr. Bhadelia, that the final frontier in creating a compassionate and just world are

era/?s=04&fbclid=lwAR2oGetAg7yEAcN7AjPlgYF8naxgyHsWnCLAdVmS-

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weathered the storms. However, recently the word has come to be co-opted to meet political ends and, in that context, its meaning altered. The government's COVID -19 response 'Bayanihan to Heal as One' Act incentivizes citizens to take actions that oppose the bayanihan spirit. This paper used the word 'Bayanihan' in its true traditional meaning and not what it has come to mean through legislation. For more information see https://asiatimes.com/2021/12/duterte-weaponizes-filipino-custom-in-the-covid-

the systems that perpetuate injustice and that they must be dismantled.

Not to write off or disregard the individual experience, but it's about moving beyond it and seeing the structural, long-term challenges there as well. And using that as the basis for the analysis.

While the ways in which compassion starting from the individual soul translates into transformation still require more exploration, the three presentations and the insights offered by the dialogues begin to give us a way of thinking about this as we seek the answers.

The palliative care circular model of 'Compassionate Community Development' presented by Stephen Connor that asserted the integration of our inner and outer worlds is an immensely helpful framework in thinking about how we build compassionate systems.

Actually, we have to really start with building compassionate individuals in communities, through mindfulness, attunement to self and others, that leads to compassionate relationships between families, caregivers, team members, organisations and systems. Through connectedness and shared humanity, we develop compassionate organisations, and build compassion into structure, and leadership, and funding for organisations, that lead to compassionate communities where there's a shared sense of belonging and solidarity.

This thesis resonates with Martin Luther King's idea of the 'beloved community' which takes the notion of justice beyond political and economic power and requires an approach that starts from our 'individual souls'. In some spaces in the development and philanthropic sectors, the work at the individual, the relational and organizational level is already happening. One participant noted a shift in their organizational culture on account of the pandemic.

I think compassion has been very important for us this year in two areas: one is our relationship with our grantees, but also in my relationships with my line reports and my trustees, in a situation where many people have been ill themselves or have been bereaved. And I have a sense that over the last 18 months we have given each other permission to bring our whole selves or our bodies to work in a way which we hadn't before - philanthropy being very cerebral. But everybody has had permission to be a physical being as well, and to make allowances for the needs of the body as well as the demands of the mind.

This point acquires more pertinence in the context of societal 'segregation' identified in the dialogue process as a barrier to compassion. Segregation can manifest in myriad ways at a systemic level such as the caste system in India noted above and other 'things that disembody us from sense of self and connectivity' and 'the role the capitalism plays in that' and the 'cold bureaucratic cultures' in our work places. A participant working with youth in a

South African township distinguished between 'knowing, feeling and doing' or 'cognition, emotion and action'. She explained how in her work, particularly in COVID times, the difficulty in the 'expression of compassion' has been remoteness and isolation. 'Often, you may feel it, you may even know it, but it's hard to do, and hard to connect.' She reinforced the idea that 'it's the practice of compassion that we may need more practice at.' Receptivity to the full experience of what it is to be human in our organizations is then a good starting point for modelling compassionate relationships in society.

The self as the beginning for building out compassion and infusing our work with it was stressed by another participant, the Director of a community philanthropy organization in central Africa. She traced a journey to becoming a more compassionate organization that was then able to integrate into its workings many of the qualities of compassionate action identified above such as agency, subsidiarity and solidarity.

We started off as a donor pooled fund in a place that didn't have much compassion because we were very much under the control of donors. But over the last 13 years we've moved from that kind of an organization to an organization that has tried to integrate compassion into our operations. And how are we doing this? Because of external factors like COVID, like climate change, like food shortages and economic crises our team has become increasingly vulnerable, and internally as we've started working with communities we have become part of communities, and we realize in order to change anything in communities, you need to become their friend. You need to be with them, you need to be part of their journey. And as we are going through all the other bits, including development training, we've realized that self-reflection is so absolutely important. Self-reflection also includes being more compassionate because once you start reflecting on your own strength and deficiencies and your own behaviour, compassion becomes automatically part of what you are.

Reflection enabled another organization in a difficult place to respond compassionately across divides in the context of deep polarization. 'It's been very challenging to actually step outside of our comfort zone, and genuinely listen and genuinely understand what the other side is, and bring that as part of institutional reform, how as an organization are we compassionate?' she wondered. She represented a pro-democracy organization working in Myanmar and was speaking in the light of the 2020 coup in the country and her interactions with people who have family members in the *junta*.

The representative of the community philanthropy fund from central Africa further drew attention to the importance of self-compassion in social change processes.

It has also on a personal level been very difficult over the last one and a half years – increasing pressures from all those external factors, including COVID. There's so much pressure on executive directors of civil society and of local grassroots organizations, and sometimes if

you continue to be under pressure and never get the support, it's very difficult to continue to be compassionate. It's like you are mistreating a child during the entire childhood and you are expecting a child to be a normal human being.

Important work in this area of facilitating healing and well-being in at the individual level so that it can then resonate outwards at a systemic level is already taking place in the sector. Two notable examples are the Compassionate Institute (already noted above) and the Wellbeing Project.

Through an iterative process of discovery and adjustment the Wellbeing Project's theory of change is that 'inner well-being leads to a deeper systems change orientation'.³² As noted above those working in social change are facing unprecedented challenges and there is a growing incidence of burnout and depression in the social sector. In their work, the Wellbeing Project found that that while 75% of respondents felt that looking after their well-being was 'very important,' merely 25% reported that they looked after their well-being 'to a great extent'.³³

To learn more about the challenges surrounding contemporary changemakers including activists, teachers, non-profit leaders, social workers, social entrepreneurs and healthcare providers, the Project conducted a study involving interviews with social change leaders from around the world, a comprehensive multi-round, sector-level Delphi study over six months with an international group of 300+ changemakers from 55 countries and undertook an 18-month Inner Development Program for three cohorts of 20 changemakers from 45 different countries. A seven-person research team followed this group over several years documenting their inner well-being journey and how that shifted the work of social change.³⁴

They found that after focusing on wellbeing, changes happened within individuals, their organizations and even across the sector. 'We found that wellbeing inspires welldoing.'

Similarly, The Compassion Institute is 'an advocate for compassion' at the individual, organizational and societal level. They too hold the view that it is 'a combination of inner/ personal and systemic transformation that will bring about the change we want to see.' They articulate their belief as follows³⁵:

- 'Each of us is shaped and conditioned by the systems and ecosystems in which we breathe, live, and work.
- In order to collectively move toward a more caring and compassionate society, it is necessary to redesign existing systems so that they are more life-giving, humane, and compassionate.
- It is not enough for individuals to cultivate our own inner capacities and

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³² http://wellbeing-project.org/wp-content/uploads/2020/03/research report.pdf

³³ https://wellbeing-project.org/wellbeingreport/

³⁴ ihid

³⁵ https://www.compassioninstitute.com/systems-transformation/

- resources, but we must also enable environments that allow for individuals to exercise, express, and develop their full humanness and best selves
- The ongoing movement for social and racial justice is a rallying cry for equity and belonging, it is a call for society to value and care for all.'

We are only at the dawn of our journey to discover how we can transform systems through compassion and how can we build the 'beloved community'. We know from the three presentations that care and compassion infused systems such as palliative care can serve to alleviate preventable suffering. Dr. Connor's humbling reminder that 'compassionate communities don't always exist spontaneously and can be nurtured' gives us hope when the world is in the grips of a 'tsunami of suffering' generated by the COVID-19 pandemic and a host of other forces. The dialogues have helped us to begin to understand the principles and behaviours that underlie compassionate development and philanthropic processes, and that can nurture compassionate communities and systems. We will continue this exploration. In the process we will learn from practitioners who are doing the work of reflection at an individual level but also translating that into their actions and building more compassionate relationships in their organizations and the communities they serve. Our ultimate aim is to understand how we leverage the personal, relational, organizational and political shifts to result in transformation across the whole system. We welcome you on this journey with us.

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