

Integrated Care and Community Services in Global Health

53

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Contents

Introduction	1652
From Process-Centered to People-Centered Systems	1653
"Culture eats strategy for breakfast" (Peter Drucker)	1655
A People-Centered Approach to Support System Change	
Integrated Care to Translate Health in All Policies into Practice	1657
The Key Elements of Integrated Care	1657
Another Piece in the Puzzle to Improve Global Health: Integrated Community Care	1659
Conclusion	1661
References	1662

Abstract

People-centeredness, integrated care, and community care all spring from the same common challenge: the understanding that our health and care systems are consistently failing both people and professionals, and the need to recalibrate and relearn some of the old wisdom of what health and wellbeing actually mean. A core tenet for all is the partnership with people and communities on all levels of the system, accepting them as equal partners in the governance, design, delivery, and evaluation of services. As an instrument to address the global health issues and support the achievement of the Sustainable Development Goals, people-centered, integrated thinking is essential to ensure sustainable, system-wide, and locally relevant change. This paradigm shift can best be summarized in changing the question from "What's the matter?" to "What matters to you?" This chapter will explore the key principles of people-centeredness, integrated

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care, and integrated community care, and discuss how these can support the tackling of global health challenges and lead to better outcomes on individual, community, and system levels.

Keywords

Integrated care \cdot Integrated community care \cdot People-centeredness \cdot Social determinants of health

Introduction

People-centeredness, integrated care, and community care all spring from the same common challenge: the understanding that our health and care systems are consistently failing both people and professionals, and the need to recalibrate and relearn some of the ancient wisdom of what health and well-being actually mean.

In most ancient cultures, whether China, India, or Mesopotamia, there existed an inherent understanding that, in order to achieve health and well-being, the physical, mental, and spiritual realms needed to be in balance. In Western culture, this was epitomized by Juvenal's dictum "Mens sana in corpore sano," a healthy mind in a healthy body. And it was ultimately enshrined in WHO's constitution (1946), which defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." George Engel (1977) translated that into the bio-psycho-social model of medicine, emphasizing the importance of the interrelationship between the body and mind of an individual with the wider socioeconomic context, in which one lives. This notion was taken up once more by the WHO Alma-Ata Declaration (1978), reinvigorating primary and community-based care models, and urging health systems to shift their focus from institutions and curative approaches to communities and preventive concepts of care. Over the following decades, however, scientific, medical, societal, and technological advances led systems to subscribe to ever more specialized, ever more institutionalized services, especially in high- and middle-income countries. At the same time, a complex mix of factors, including the demographic shift, globalization and urbanization, have led to a shift from acute to chronic diseases across the world. In low-income countries, this created the "Double Burden of Disease" (WHR 1999) adding the need for chronic disease management to the persistent challenge of dealing with infectious diseases and accidents. On another front, 2016 marked the first year in history that more people were overweight or obese, than underweight (Ezzati et al. 2016), highlighting the global scale of lifestyle-related risk factors and morbidity caused by a more sedentary lifestyle, the exponential rise of processed foods, and a built environment not conducive to physical activity.

Mirroring these developments, another milestone in the understanding of the interplay between individual physical and mental health and the social environment was reached in the formulation of the "social determinants of health" (Wilkinson and Marmot 2003; WHO 2008). Based on Marmot's Whitehall studies (Marmot et al.

1978, 1991) this concept underscores the intricate influence that education, social status, the environment, and infrastructure have on the individual health status and well-being of a person throughout their life course and notwithstanding their relative income or power. Social determinants of health go hand in hand with the call for a "health in all policies" and a whole-of-system/whole-of-government approach, propagated by WHO and reinforced by the "Sustainable Development Goals (SDGs)."

Giant strides have been made to combat diseases, introduce public health measures, improve food security, and accelerate economic development. Advances in medicine and technology have increased life expectancy around the world, halved child mortality rates, and often turned disease-related mortality into manageable morbidity. But this evolution was not mirrored in our health and care systems, which are still stuck in century-old thinking and structures, adhering to obsolescent boundaries and hierarchies between specialities, sectors, and systems. They are still focused on fixing episodic, acute, organic diseases, leaving little space to consider the whole person, let alone the social environment. They are built around pathogenetic procedures and structures to serve the organizations in it, and not around a salutogenetic understanding of individuals and families as partners in care. Current health and care systems around the world are static, reactive, and risk-averse, which very often leads to scarce resources being wasted on interventions and technologies, rather than people and communities. Most resources however, both human and financial, are still poured into hospitals and institutions rather than into primary and community care. The COVID-19 pandemic has put into high relief, what many experts working in the field have been saying for years: health and care need a paradigm shift to a more integrated, people-centered system (Amelung et al. 2017; Stein et al. 2020).

WHO has promoted various concepts to support this shift, including the WHO global strategy on people-centered and integrated health services (2015a, 2016), and the Astana Declaration (WHO 2018), which both emphasize the need for more coordinated, context-specific, and population-based service delivery systems. A tenet is the partnership with people and communities on all levels of the system, accepting them as equal partners in the governance, design, delivery, and evaluation of services. This chapter will explore the key principles of people-centeredness, integrated care, and integrated community care, and discuss how these can support the tackling of global health challenges and lead to better outcomes on the individual, community, and system levels.

From Process-Centered to People-Centered Systems

The concept of social determinants of health is well established in principle; however, few policy makers, professionals, or people realize what this means in actual fact: that 90% of an individual's health outcomes are influenced by factors other than access to clinical care, prominently among them lifestyle choices and the living environment, as illustrated in Fig. 1 (Gnadinger 2014; Hood et al. 2016; N.N. 2008).

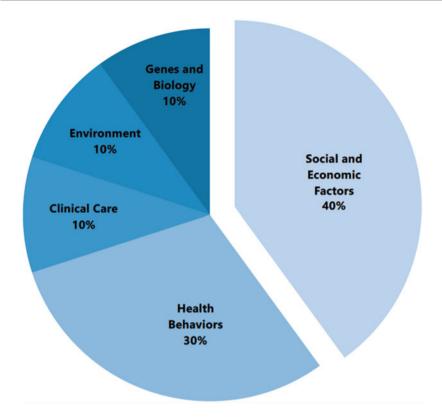


Fig. 1 Multifactorial determinants of health. (Source: Illustration based on numbers published in N.N. (2008), Gnadinger (2014), and Hood et al. (2016))

These numbers should be enough for anyone to take action and promote the "Health in All Policies" approach formulated by WHO on a systems level. Other global health topics, whether it is climate change, globalization or digitalization, all need a similarly concerted effort, as outlined by the SDGs. Crucially, this asks for a major cultural change and paradigm shift in how systems think about health and wellbeing.

But what does this actually mean? According to the Oxford English Dictionary, a system is "a set of things working together as parts of a mechanism or an interconnecting network; a complex whole" or "a set of principles or procedures according to which something is done; an organized scheme or method." System change thus means either removing or adding parts, or bringing the parts of a system to work in very different ways. While it is difficult enough to change set principles or procedures, it is a Herculean task to change the people implementing or enforcing these. Everyone knows how hard it is to change personal habits, and fulfill recommendations, whether it be eating healthier food, stop smoking, or increasing physical activity. Changing the way systems work means changing the way people work — and that is only possible, if people believe this change is necessary, attainable, and

representative of their personal values and beliefs. How powerful people movements can be has recently been illustrated by global movements like #MeToo, FridaysforFuture, or Black Lives Matter. They all, in essence, call for a global culture change, which hopefully translates into wider systems change.

"Culture eats strategy for breakfast" (Peter Drucker)

Culture and values are now recognized as a driving force in the delivery of high-quality services in general, and health and care in particular (e.g., Braithwaite et al. 2017; Mannion and Davies 2018). Culture, or "the way we do things round here," influences the way people work, how they prioritize tasks and how they interact with each other. Thus, it can be a major driver for change or, more often than not, the ultimate reason why reforms or reorganization fails (Willis et al. 2016; Miller et al. 2016; Braithwaite et al. 2017). An enabling and learning culture is seen to promote opportunities for identifying, reflecting, and acting on any concerns in organizations, while a controlling and blaming culture is seen to stifle such concerns being raised and responded to appropriately (Willis et al. 2016).

Values, which may be expressed in the mission and strategy of organizations, or which practically influence everyday decisions made by individuals and teams, are key features of culture (Carroll and Quijada 2004). But values themselves are a complex set of different influences, which are acquired and reflected by such varying forces as faith, sociocultural background, or political opinions, in addition to the professional and organizational values (Woodbridge and Fulford 2004; Mangan et al. 2015). It is therefore not surprising, that the clashes in values and culture which may emerge through new arrangements can be a powerful obstacle as the parties involved are exposed to alternative ways of seeing and interpreting the world and threatened by new cultures and values taking over (Cameron 2011; Miller et al. 2016).

A People-Centered Approach to Support System Change

So, in order to change systems and cultures and embrace a more holistic understanding of health and well-being, people-centeredness needs to be a guiding principle. This has been set out, among other documents, in the WHO global strategy on people-centered and integrated health services (2015a), as well as in the Quadruple Aim of health systems (Bodenheimer and Sinsky 2014). There are many terms to capture the core notion of engagement, involvement, and participation (e.g., Ferrer 2015; Miller et al. 2016). Similarly, "people-centered," "people-focused," "people-driven," and "people-powered" have all been used in scientific and gray literature to capture the nuances of how involved people, that is, individuals, families, communities, and civil society, are in the design, delivery, and monitoring of health and care systems. In essence, they all call for the same thing – an equal partnership between policy makers, professionals, and people to co-design systems and services

according to the needs of the people who use them (WHO 2007, 2015a; Marmot et al. 2008; Horne et al. 2013; Miller et al. 2016).

The people-centred approach meets these broader challenges by recognizing that before people become patients, they need to be informed and empowered in promoting and protecting their own health. There is a need to reach out to all people, to families and communities beyond the clinical setting. In addition, health practitioners are people, and health care organizations and systems are made up of people. Their needs should also be considered, and they must be empowered to change the system for the better. That is, a people-centred approach involves a balanced consideration of the rights and needs as well as the responsibilities and capacities of all the constituents and stakeholders of the health care system. (WHO 2007, p. 5)

In 2008, Coulter et al. asked: where are the patients in decision making about their own care, and this question still rings true today (WHO Europe 2008). Ferrer (2015), in her comprehensive report for the WHO Regional Office for Europe, and Miller et al. (2016) give an extensive overview of the different levels and tools of individual and community involvement in the decision making about health and care, from shared decision making and shared care plans, via membership in management boards to co-designing policies and system reforms. There are many ways and a plethora of good examples around the world to illustrate that co-designing people-centered systems can work, and if done properly, it will bring better outcomes for everyone involved (Ferrer 2015; WHO 2015b). Figure 2 illustrates the different steps along the way to truly people-centered systems, adapted for this purpose from the Ladder of Citizen Participation (Arnstein 1969). Currently, most efforts are still focused on educating and informing patients, sometimes including family members

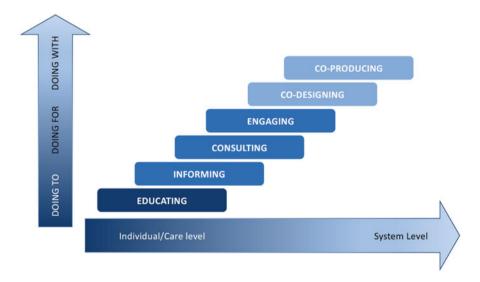


Fig. 2 Ladder of participation to support people-centered systems. (Source: Illustration by the author, based on Arnstein (1969))

and informal carers, rarely taking the wider community (and its assets) into account. While there are some truly inspirational examples, like the Southcentral Foundation's NUKA system of care in Alaska (https://www.southcentralfoundation.com), or the Te Whānau O Waipareira Trust in New Zealand (https://www.waipareira.com), most models have just moved from "doing to" to "doing for," and the leap to "doing with," though crucial, is often met with suspicion and fear (Miller and Stein 2020; WHO 2015b; National Voices 2013).

The shift from patho- to salutogenesis represents a profound paradigm shift, which touches at the cultural, financial, and structural core of our systems (Goodwin et al. 2017). Involving people in all the conversations is a proven instrument to focus the discussion on the essentials, improve the quality of decisions taken and the overall satisfaction of everyone involved (Ferrer 2015; WHO 2007, 2015b; Bodenheimer and Sinsky 2014). As an instrument to address the global health issues and support the achievement of the SDGs, people-centered thinking is essential to ensure sustainable, system-wide, and locally relevant change.

Integrated Care to Translate Health in All Policies into Practice

Integrated care is an umbrella term for a multitude of models, concepts, and tools which have been developed over the past few decades to implement people-centered care and answer to the challenges outlined in the introduction, whether it be the demographic shift, the rise of chronic diseases, or the need to address the social determinants of health (e.g., Goodwin et al. 2017; WHO 2015a; Shaw et al. 2011; Miller et al. 2016; Valentijn 2016). The plethora of models has led to an equally rich literature on how to define integrated care, from a more process-based (e.g., Kodner and Spreeuwenberg 2002), to a system-based (e.g., WHO 2016), to a peoplecentered definition (e.g., National Voices 2013). It is this last definition, which will be used to guide the further discussion, as it represents the shift from "doing for" to "doing with." The definition is taken from a series of "I-statements" which were the result of a public enquiry in the English NHS about the expectations the population had about their care services. Accordingly, integrated care is defined as: "I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me" (National Voices 2013).

The Key Elements of Integrated Care

The opaque nature of integrated care are both the strength and weakness of the approach, as it allows the necessary flexibility for people to adapt it to local context and needs, but it also makes comparison and systemwide promotion difficult, as everyone tries to come up with their own interpretation of the term (Goodwin et al. 2017). Notwithstanding the lack of a universal definition, the evidence and experience across the world and on all levels of the system have enabled the emergence of

key principles and building blocks, which need to be put in place in order to promote a more integrated, coordinated, and people-centered model of care. One of the first models to formulate such key elements was Wagner's Chronic Care Model and its adaptations (Barr et al. 2003; WHO 2002; Wagner et al. 1999). The WHO global strategy for integrated, people-centered health services (WHO 2015a; 2016), WHO Western Pacific Region's People-centered policy framework (WHO 2007), and the WHO European Framework for Action on Integrated Health service delivery (WHO Europe 2016) brought the concept to a global level, at once emphasizing its universal relevance and the need for regional and local adaptation. Based on field studies, literature reviews, the analysis of case examples, and the development of evaluation frameworks for the aforementioned models, the cumulative evidence of what needs to be done in order to improve service delivery and system outcomes is clear (Suter et al. 2009, 2017; González-Ortiz et al. 2018; Leijten et al. 2018; Amelung et al. 2017; WHO Europe 2016; Miller et al. 2016; Valentijn 2016).

Overview: Key Elements for Integrated, People-Centered Systems

- Centering on people, families, and communities: the perspective of the person, family, and community need to be taken as the guiding principle in any decision-making process, design, or delivery of care.
- Integrated, coordinated, and evidence-informed management of health
 and care services: based on the people-centered perspective, care pathways, service delivery processes, and structures need to be adapted to
 enable "the right services, in the right place, at the right time and by the
 right people." This includes public health and prevention just as much as
 municipal, social, or legal services, depending on the priorities of the
 community.
- In order to deliver such services, interdisciplinary, cross-sectoral team
 work is a prerequisite together with appropriate, innovative, and userfriendly information and communication technologies. These do not
 always have to be high tech. A short phone call or face-to-face conversation
 often is more effective and transmits more information than a string of
 emails. The importance lies in the transparent and accessible transmittance
 of information to everyone in the system requiring it, including the individual and family.
- All of these activities need a new understanding of managing and leading such organizations and systems, taking a distributive and shared approach to accountability and governance, and actively promoting the values necessary to achieve culture change.
- Ultimately, there is a need to develop learning organizations, with the
 help of continuous monitoring and evaluation frameworks, open feedback loops and rapid learning cycles. This will help create organizations
 and systems, which are flexible enough to deal with crises or unprecedent
 events and answer to the ever more complex challenges in global health.

Even though a lot has been written about the need for systemic and policy change, the evidence has also shown that "all integrated care is local." As health and care services need to be adapted to meet the needs and priorities of communities, it is these communities who need to set the stage and be involved. And this necessitates a certain degree of locality in order to implement the necessary tools and instruments in practice. While the vision, strategy, and regulatory framework on the systems level creates the conditions for change, the actual change comes to life on the ground with local people, providers, and organizations shaping the system according to their needs (e.g., Kuluski et al. 2019; Amelung et al. 2017; WHO 2016; Ferrer 2015; Booker et al. 2015). This paradigm shift can best be summarized in changing the question from "What's the matter?" to "What matters to you?" (Nies et al. 2017, S376).

Creating a map of care (Fig. 3) is a useful depiction of this change in perspective, while at the same time highlighting the many stakeholders and services available to people and their families. In the absence of an integrated care approach, these need to be identified, navigated, and coordinated by the individuals and their informal carers themselves – a task that is often overwhelming and frustrating. Turning this exercise into a positive experience, a map of care can also support the co-design of an integrated care network, creating a shared sense of purpose and highlighting to professionals that they, too, are not alone and can seek help through sharing responsibilities and co-managing care.

Another Piece in the Puzzle to Improve Global Health: Integrated Community Care

Combining and advancing the principles of people-centeredness and integrated care, integrated community care shifts the focus on communities as the true innovators and drivers for change. Using goals-based and asset-based approaches, integrated community care embraces the strategies and ideals set out in the WHO Alma Ata (1978) and Astana (2018) declarations, the efforts to move toward universal health coverage and the SDGs, and brings them down to the level where change actually takes shape on a day to day basis. The aforementioned grassroots movements illustrate that such communities can cross borders and span the globe, in their efforts to improve health, quality of life, and personal functionings. The bulk of the work, however, takes place unseen and unsung in community health centers, local clubs and associations, or neighborhood support networks.

As part of the TransForm project (https://transform-integratedcommunitycare.com), a group of philanthropic foundations from Europe and Canada, brought together policymakers, professionals, and local communities to discuss the nature and elements of integrated community care. One of the results of this four-year journey was a set of seven effectiveness principles grouped into three domains, which were formulated as a foundational basis to establish integrated community care as the norm (Vandenbroeck and Braes 2020, p. 8).

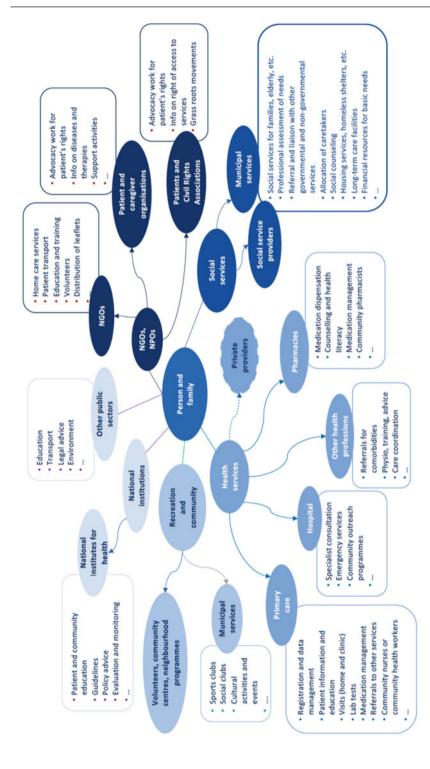


Fig. 3 A map of care. (Source: Own Illustration, based on Gabe's map of care, Lind and Antonelli n.d.)

Co-develop Health and Well-Being, Enable Participation

- Value and foster the capacities of all actors, including citizens, in the community to become change agents and to coproduce health and wellbeing. This requires the active involvement of all actors, with an extra sensitivity to the most vulnerable ones.
- Foster the creation of local alliances among all actors which are involved in the production of health and well-being in the community. Develop a shared vision and common goals. Actively strive for balanced power relations and mutual trust within these alliances.
- 3. Strengthen community-oriented primary care that stimulates people's capabilities to maintain health and/or to live in the community with complex chronic conditions. Take people's life goals as the starting point to define the desired outcomes of care and support.

Build Resilient Communities

- 4. Improve the health of the population and reduce health disparities by addressing the social, economic, and environmental determinants of health in the community and investing in prevention and health promotion.
- 5. Support healthy and inclusive communities by providing opportunities to bring people together and by investing in both social care and social infrastructure.
- 6. Develop the legal and financial conditions to enable the co-creation of care and support at community level.

Monitor, Evaluate, and Adapt

7. Evaluate continuously the quality of care and support and the status of health and well-being in the community by using methods and indicators which are grounded within the foregoing principles and documented by participatory "community diagnosis" involving all stakeholders. Provide opportunities for joint learning. Adapt policies, services, and activities in accordance with the evaluation outcomes.

Reflecting on these domains and seven principles, it becomes evident that the core tenets of integrated community care reinforce and reiterate those set out for people-centeredness and integrated care. It also highlights the fact, that, as challenges become more complex and less predictable, systems, organizations, professionals, and communities need to adapt their ways of working and thinking to allow more flexible and emergent approaches to evolve. Communities have been the backbone of health and care systems since time immemorial. Long before the establishment of, and in modern times in the absence of, formal services, it was the local communities, which took care of their own and innovated in times of crisis (Vandenbroeck and Braes 2020; Ferrer 2015).

Conclusion

The COVID-19 pandemic magnified the disconnect between policy makers, academia, people, and communities, particularly for vulnerable and underserved groups who faced even more inequalities, largely based on social determinants of health.

Informal carers were left unsupported, communities were left behind, and service delivery reverted back to old school, paternalistic, and clinically driven cure. On the other hand, the past few years have magnified on a global scale, how powerful community-driven movements can be with a common vision and the apt utilization of new technologies. But however strong these movements are, systemic, sustainable change is difficult to achieve. The journey from static disease-repair system to complex adaptive health and care system is long and arduous and it needs resilience, endurance, and constant repetition to make it happen. Despite the overwhelming evidence on the social determinants of health and the need for people-centered, integrated systems, there is still no health and care system in the world, which can claim to be truly people-centered, and it may be that it needs another 50 years for this concept to gestate and become ingrained in our structures, processes, and culture. It is hoped that this will not be the case, as many global health issues demand a radical shift in health and care. Ultimately, it will be the people and communities who will decide what kind of system they want to work and care in.

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