

Volker Amelung · Viktoria Stein ·
Esther Suter · Nicholas Goodwin ·
Ellen Nolte · Ran Balicer *Editors*

Handbook Integrated Care

Second Edition

 Springer

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Editors

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Preface

Only two years after publishing the first edition of this handbook, we started working on a second edition. Three reasons were responsible for why we thought that a second edition should be published quite soon after the first one: first, even though the first edition had already more than 600 pages, we felt that some important topics were missing and therefore gaps need to be closed. Secondly, the research field changed quite dramatically and an intensive new discussion about ecosystems, population health management and their development evolved. The final reason came up unexpectedly during the preparations for this edition. COVID-19 made it very clear that strategic thinking about health system design and population health management is not a nice to have, but one of the most fundamental questions we are facing today.

The gaps we tried to close in this second edition are new chapters on people-centredness, complexity theories and evaluation methods, additional management tools and many more experiences from different countries and localities.

While there are still many different definitions and frameworks for integrated care available, a common understanding on the key building blocks of integrated care has emerged nonetheless. As we hear so often, it is not the “what is integrated care”, which eludes us, it is the “how” of implementation.

There are mainly three different ways to look at integrated care: integrated care as a theoretical framework of how to organize our health systems, such as Ed Wagner’s chronic care model or WHO’s global strategy on integrated people-centred health services. These concepts are generic and focus on the way how we should think about healthcare provision. They are more like a compass, explaining the right way to think and defining the key elements, without giving specific instruction of how to execute it. These frameworks are referenced throughout this book as guiding lights in theory and practice.

Secondly, integrated care could be understood as a health system design tool to answer to (context-specific) challenges. Some of the most advanced examples, such as Scotland, the Basque country, Singapore or Canterbury, are described in more detail in Part B of this book. The focus here is on a whole-of-system design, which is very slowly moving towards a health in all policies understanding. This is mainly a (health) policy and political decision, defining the strategy and way forward for countries or regions.

Lastly, integrated care could be understood as a business model, for example hospitals or insurance companies investing in extending their value chain or expanding their scale and scope. In this case, integrated care is used as a strategy from different players to differentiate themselves in a competitive market, be it among primary care practices, hospital networks or private service providers. If it is seen primarily as a business model, with income generation as its primary aim, then this bares many obvious problems. There are hybrid forms, however, which argue that better and more integrated care ultimately brings better financial outcomes as well. Many ACOs and Health Maintenance Organizations (HMOs) in the USA are examples of this approach. The key lesson here is that it is futile to deny that there are huge financial interests playing out in the background, and financial disincentives to coordination and integration abound in every system.

All three approaches are highly valuable for the discussion about integrated care, but it is crucially important to make the intentions transparent. Ideally, integrated care could be both, a health system design and a convincing strategy for market participants, too. In relation to this, one of the most fascinating emerging topics is around evolving healthcare ecosystems. Again, there are two, diametrically opposed views on what healthcare ecosystems are in the first place. Based on systems theory, complex adaptive systems and similar theories, ecosystems can be understood as idealistic entities of numerous interdependent agents sharing values and goals. On the other hand, ecosystems such as Amazon, which are sophisticated, transnational and data-driven technical platforms, might become an alternative to healthcare systems, offering both—financing and provision of services. We might not like it, but other business giants like Google, IBM or Philips are all competing for a slice of the lucrative healthcare market. This development needs to be observed very carefully, as they offer both—more patient orientation, but also loosening the control of health system planning.

This second edition was finalized during the COVID-19 shutdown in most of our countries. Even if we are still far away today to judge on the right strategies and correct policies, the pandemic made blatantly obvious that public health and health services research is fundamental for a well-prepared and responsive health and care system. COVID-19 further underlines the need for more evidence-informed policy-making and interdisciplinary decision-making. We need to understand health and the management of crises as a continuous, emergent issue, with many unknowns, which require flexible and innovative approaches. In order to be able to learn from the crisis and better prepare for future outbreaks, we need to ask the right questions, invest in sound research and not sacrifice research principles due to the urgency and pressure of the crisis. This is much in line with what is required in any integrated care approach as well. COVID-19 has accentuated the stark reality that, despite the efforts of the past 20 years, there remains a continued failure to embrace integrated care systems. It has also demonstrated how quickly systems, organizations and individuals can change, if they must. As an international community of research and practice in integrated care, we must make sure not to waste this opportunity and help make the change stick.

This extensive second edition of the handbook would not have been possible without the help of many colleagues and staff members. A special thanks goes to Anna-Sophia Bilgeri, who dedicated many hours, emails and unabating positive energy to the tedium of following up with authors, keeping the editors on their toes and integrating the different pieces of this book. We are also grateful to Dr. Johannes Glaeser and Judith Kripp of Springer Verlag for their patience and continual support in the realization of this project. Ultimately, this book could not have been done without the contributions of the many authors and their willingness to share their expertise and experience with the reader.

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Part I
Foundations of Integrated Care

What is Integrated Care?

1

Nicholas Goodwin, Viktoria Stein, and Volker Amelung

1.1 Introduction

Integrated care is a concept that is now widely used and accepted in different health and care systems across the world. Yet the concept is not new since concerns about fragmentations in the way care is designed and delivered have a long historical lineage. The origins of the term date back to the ancient Greeks who recognised the need to treat people's mental health alongside their physical symptoms. In more recent times, integrated care as a terminology became commonplace in the 1970s in the fields of child and adolescent health as well as long-term care for the elderly.

By the late 1970s, one of the strongest drives towards more integrated and coordinated care provision emerged from the birth of the primary healthcare (PHC) movement following the World Health Organisation's Alma-Ata Declaration on Primary Health Care in 1978 (WHO 1978). Strengthening primary health care has subsequently been the cornerstone for action in health sector reforms worldwide with good evidence to demonstrate its impact in terms of health system strengthening and promoting universal health coverage (WHO 2008).

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A key element to the PHC movement has been to improve what Barbara Starfield termed the ‘four C’s’ of primary care: accessible contact; service coordination; comprehensiveness; and continuity of care (Starfield 2002). So, in the most fundamental of ways, a key role of the PHC movement has been to promote the delivery of more integrated care to people living in local communities. This PHC movement has been sustained to the present day where initiatives, such as multi-speciality community providers in England and the patient-centred medical home model that originated in the USA, underpin their rationale through such evidence.

In parallel to the PHC movement has been the global response to the growth of age-related chronic illnesses and comorbidities. The development of the Chronic Care Model (CCM) and its variants (Wagner et al. 1999) has been of specific importance in tackling this growth. The CCM has become accepted in many countries as the comprehensive framework for the organisation of health care to improve outcomes for people with chronic conditions. The model focuses on six key and inter-related components including: support for self-management; decision support to professionals; care coordination and case management; clinical information systems; and community resources to promote healthy living; and health system leadership (Wagner et al. 1999).

The development of the CCM came in recognition that most health systems were failing to meet the needs of people with chronic illnesses since they remained largely built on acute, episodic models of care rather than care that focuses on more longitudinal, preventive, community-based and integrated approaches. The CCM has thus been a catalyst to help reorient systems of care to become more integrated in the management of chronic illness that has strengthened PHC and promoted self-management and patient empowerment.

More recent variations of the CCM model have focused on including the broader determinants of health with coordinated interventions that cut across the primary, secondary and tertiary levels of care and that extend beyond the boundaries of the healthcare system to cover issues such as public health (i.e. population health promotion, prevention, screening and early detection), rehabilitation and palliative care (Barr et al. 2003; WHO 2002). Indeed, approaches to develop population-based ‘managed care’ organisations have emerged not only as a policy imperative in many countries (e.g. such as through the development of Integrated Service Organisations in the Basque Country) but also as a business strategy [e.g. such as Kaiser Permanente in the USA and *Gesundes Kinzigtal* in Germany—see the Case Studies (Part 6)].

PHC, CCM and approaches to ‘managed care’ have been significant steps towards integrated care. Yet, many existing programmes continue to use a vertical and disease-oriented approach to care when the evidence suggests that better outcomes occur through adopting an integrated approach between health care and other sectors that is more preventative and community-based. Disease-based approaches tend to foster duplication and the inefficient use of resources and produce gaps in the care of patients with multi-morbidity. The structural solutions in the way care has been organised to promote chronic care require reappraisal if the ultimate

Table 1.1 Aspects of care that distinguish conventional health care from integrated care (adapted from WHO 2008, p. 43)

Conventional ambulatory medical care in clinics or outpatient departments	Disease management programmes	Integrated care
Focus on illness and cure	Focus on priority diseases	Focus on holistic care to improve people's health and wellbeing
Relationship limited to the moment of consultation	Relationship limited to programme implementation	Continuous care to individuals, families and communities across the life course
Episodic curative care	Programme-defined disease control interventions	Coordinated and people-centred care integrated around needs and aspirations
Responsibility limited to effective and safe advice to the patient at the moment of consultation	Pro-active management of a patient's risk factors to meet targets	Shared responsibility and accountability for population health, tackling the determinants of ill-health through systems thinking and inter-sectoral partnerships
Users are consumers of the care they purchase	Population groups are targets of specific disease control interventions	People and communities are empowered to become co-producers of care at the individual, organisational and policy levels

objective is to promote more people-centred integrated care. Table 1.1 attempts to provide an understanding of how the characteristics of integrated care should be distinguished from that of conventional care and approaches to disease management.

Most recently, there has been a surge in interest in how integrated care needs to be 'people-centred' and embrace patients and service users as partners in care and to ensure services are well coordinated around their needs (e.g. see Blomfield and Cayton 2009; Ferrer 2015; The Health Foundation 2011, 2012). More broadly still, the notion of integrated care has gone beyond the borders of the health and social care systems to think more strategically about how to embrace the social determinants of ill-health through bringing together the wider range of community assets to promote public health, prevent ill-health and secure wellbeing to populations.

This complex and emergent story of the focus and rationale for integrated care perhaps explains why there remains a lack of a common definition for integrated care which is universally accepted. Integrated care is, and remains, a polymorphous concept that has been applied from several disciplinary and professional perspectives and which is associated with diverse objectives. This diversity therefore represents a challenge to policy-makers, managers, professionals and researchers alike in developing 'common ground' in their understanding to the meaning and logic of integrated care.

This opening chapter, therefore, seeks to respond to the commonly asked question ‘*what is integrated care?*’ To do so, the chapter briefly examines the rationale that lies behind integrated care before seeking to make sense of various attempts that have been made to define it. The chapter then seeks to outline the core aspects of integrated care and reviews how a range of models and frameworks have been (and are being) created to understand the building blocks and dynamics of integrated care systems. The chapter concludes with some forward thinking on integrated care as an evolving science.

1.2 The Rationale for Integrated Care

Notwithstanding the long history to the origins of the term, integrated care as an ongoing policy concern has come as a response to the significant shift in global demographics that has seen age-related and long-term chronic conditions replace communicable disease as the most significant challenge facing all health and care systems. This shift means that the economic burden of chronic illness now represents as much as 80% of expenditure on health (Nolte and McKee 2008). This growth is significantly associated with ageing populations. For example, it has been estimated that by 2050, more than 6% of all people in the European Union (still including the UK) will be aged over 85, which translates into more than 31 million people in absolute numbers. The number of centenarians will increase five times from 2018 to 2050, to more than half a million (Eurostat 2019). More than one-fifth of those aged 85 and over will be living with five or more comorbidities (concurrent physical and mental health needs) (European Commission and Economic Policy Committee 2009). Similar increases are projected for most countries around the world, irrespective of income levels. 2018 was the first year that people aged 65 and older had outnumbered children under the age of 5 globally (UN 2020).

Coupled with ageing populations is a dramatic increase in the use of long-term care by older people. For example, a comparative analysis on long-term care services in Europe projected dramatic increases in the use and costs of long-term care (more than 300% in the case of Germany) between 2000 and 2050 (Comas-Herrera and Wittenberg 2003). More recently, long-term care spending in the EU was the only healthcare service registering a continuous increase from 2004 to 2016, that is, throughout the financial crisis, with an average between 2 and 4% over this time period (OECD and European Union 2019). Therefore, community-based and home-based alternatives to institutionalisation in residential homes through the deployment of multi-disciplinary professional teams have become a commonplace response (e.g. Leichsenring et al. 2013; de Bruin et al. 2020).

These projections in the future demands on health and long-term care systems are observed to be so acute that even the World Health Organisation has passed a resolution across its 194 member states to adopt a *Framework on Integrated People-Centred Health Services* (WHO 2016). In their interim report, it was argued that unless a people-centred and integrated health services approach is adopted,

health care will become increasingly fragmented, inefficient and unsustainable (WHO 2015, p. 7). In other words, integrated care represents a fundamental paradigm shift in the way health and care services must be funded, managed and delivered.

The case for making such a change towards integrated care is a compelling one. Since the future of our health and care systems is increasingly shaped by ageing populations, urbanisation and the globalisation of unhealthy lifestyles, it is clear that current approaches to care that focus on curative, specialist-led and hospital-based services need to be revised. People living with non-communicable diseases (NCDs), mental health problems, and long-term and multiple comorbidities need to make strenuous efforts to access the care they need and too often find themselves disempowered, disengaged and unable to manage their health needs. By missing the opportunity to promote health and prevent complications care has become more complex and more expensive.

The hypothesis underpinning integrated care, therefore, is that it represents an approach to promote quality improvement among people and populations where care is currently fragmented and poorly coordinated. Indeed, it has increasingly been recognised that integrated care should be seen as a means to promoting the ‘*Triple Aim*’ goals in care system reform (Berwick et al. 2008): greater cost efficiency; improved care experiences; and improved health outcomes. Bodenheimer and Sinsky (2014) expanded this to the ‘*Quadruple Aim*’ adding the experience of the workforce as a crucial fourth objective to a high-quality health system. It is for this reason, in times of scarce resources and growing demands, that so much hope and weight have been placed on the integrated care movement as a mechanism for system transformation. Integrated care represents an approach to strengthen and/or introduce a set of fundamental design features for health systems that can generate significant benefits to the health and health care of citizens, whether rich or poor.

As this Handbook will reveal, the positive impact of integrated care can be seen to accrue at the level of the individual patient as well as to communities and care systems. Yet, in many areas such as health economics, such impact remains contested, and there are also significant issues in understanding how best to deploy integrated care initiatives in practice. Nonetheless, given the projections on the future demand for health and care services, we are past the ‘tipping point’ where action needs to be taken to transform care systems. The move to more people-centred and integrated care is a core strategy in that task.

1.3 Defining Integrated Care

Integrated care is a concept that is widely used, but recent literature reviews have uncovered more than 175 overlapping definitions and concepts linked with the term (Armitage et al. 2009). This large number of definitional possibilities demonstrates that they tend to be either generic or disaggregated in nature to reflect the complexity and multidimensionality of the concept. Over many years, a plethora of

terms have been used including: ‘managed care’, ‘coordinated care’, ‘collaborative care’, ‘disease management’, ‘case management’, ‘transmural care’, ‘continuity of care’, ‘seamless care’, ‘service-user-centred care’ and many others.

This ‘confusion of languages’ stems from different meanings and objectives that various stakeholders within care systems attribute to the term. This might relate to differing professional points of view (e.g. clinical vs. managerial; professional vs. patient) or from the disciplinary perspective of the observer (e.g. public administration, public health, social science or psychology) (Nolte and McKee 2008). Work by Shaw et al. (2011) provides a graphic representation of some of these different viewpoints (see Fig. 1.1). It should be recognised from this that different

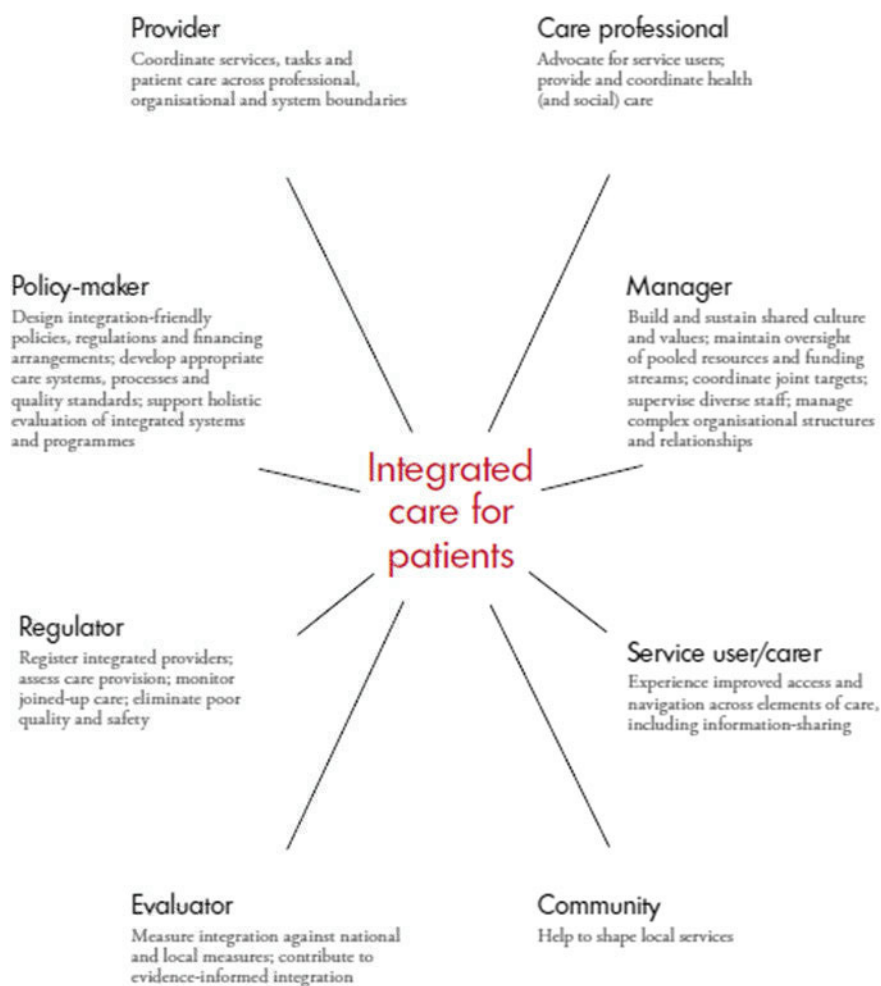


Fig. 1.1 Perspectives shaping integrated care (Shaw et al. 2011, p. 13)

interpretations and meaning of integrated care are *all* potentially legitimate. This suggests that integrated care as a concept cannot be narrowly defined in its meaning, but must be seen as an umbrella term—perhaps linked to a set of broader ideas and principles—that captures this wide-ranging set of viewpoints.

In considering the variability in the way integrated care has been defined, let us consider the five definitions presented in Box 1.1. The first of these definitions, from the World Health Organisation, imbues integrated care with the qualities of care coordination as a continuous support process over time. It is focused on the delivery of public health or clinical interventions and is largely bounded within the confines of health care (WHO 2015). The second definition, used, for example, to underpin integrated care strategies in the Basque country, is again different since it primarily discusses the importance of the structural re-organisation required to enable care organisations to work together collaboratively (Contandriopoulos et al. 2003). The third definition represents a more whole-system definition where healthcare services are integrated with other care services (Leutz 1999) in contrast to the more limited fourth definition that focuses on chronic care only (Nolte and Pitchforth 2014). The final definition is lengthier but seeks to describe the complexity and inter-sectoral nature of integrated care as a process. It also has the added advantage of distinguishing between integration (the process by which professionals and organisations come together) and integrated care (which is the outcome as experienced by service users). This is an important distinction since it implies that integrated care should only be judged successful if it contributes to better care experiences and outcomes for people (Goodwin and Smith 2012).

Box 1.1 Four Commonly Used Denitions of Integrated Care

1. A health system-based definition

“The management and delivery of health services such that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, through the different levels and sites of care within the health system, and according to their needs throughout the life course” (WHO 2015).

2. A health care manager’s definition

“The process that involves creating and maintaining, over time, a common structure between independent stakeholders (and organisations) for the purpose of coordinating their interdependence in order to enable them to work together on a collective project” (Contandriopoulos et al. 2003)

3. A whole of systems’ definition

“The search to connect the healthcare system (acute, primary medical and skilled) with other human service systems (e.g., long-term care, education and vocational and housing services) to improve outcomes (clinical, satisfaction and efficiency)” (Leutz 1999).

4. A definition from the chronic care perspective
 “Initiatives seeking to improve outcomes for those with (complex) chronic health problems and needs by overcoming issues of fragmentation through linkage or coordination of services of different providers along the continuum of care” (Nolte and Pitchforth 2014).
5. A process-based definition
 “Integration is a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for people by cutting across multiple services, providers and settings. Where the result of such multi-pronged efforts to promote integration lead to benefits for people the outcome can be called ‘integrated care’” (adapted from Kodner and Spreeuwenberg 2002).
6. A person-centred definition
 “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 2011).

However, the criticisms behind these well-used definitions are that they treat integrated care as a set of systemic or organisational processes as opposed to the essential quality of ‘caring’ for people. Hence, the final definition seeks to define integrated care from the person’s perspective such that the terms might have meaning to the end user (National Voices 2011). This definition was developed by National Voices in the UK to create for NHS England a defining narrative for the national strategy to promote integrated care and support. By consulting with people across its 130 health and social care charities, National Voices asked what matters most to patients and service users and produced a series of ‘I statements’ on how care and services should be integrated around their needs with a core focus on care planning, care transitions, communication, information and shared decision-making towards specific goals and outcomes.

What is implicit to all of the definitions presented in Box 1.1 is the notion that integrated care should be centred on the needs of services users, their families and the communities to which they belong (Shaw et al. 2011). Indeed, there is evidence to suggest that the more successful integrated care programmes require the common language of *people-centeredness* to create a unifying narrative across stakeholders with potentially very different professional, organisational and political objectives (Ham and Walsh 2013).

As Goodwin and Alonso (2014) point out, there is good reasoning behind developing such a ‘people-led’ definition to integrated care. For example, in reflecting on the real-life context of a patient with advanced dementia and his principal carer (his spouse), it has been demonstrated how a highly diverse,

Alzheimer Web of Care

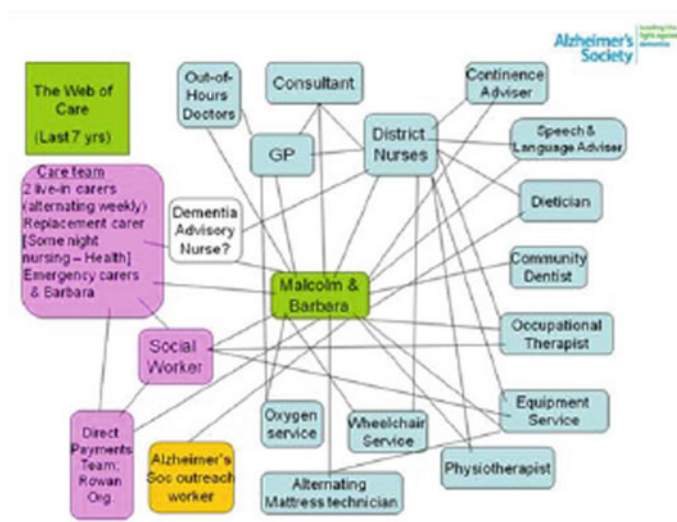


Fig. 1.2 Tackling complexity: the Alzheimer web of care (National Voices 2011)

complex and largely unconnected ‘web of care’ can result from fragmented health and care systems (National Voices 2011) (Fig. 1.2). These fragmentations are manifest in a range of key problems including:

- *a lack of ownership* from the range of care providers to support ‘holistic’ care needs;
- *a lack of involvement of the patient/carer* in supporting them to make effective choices about their care and treatment options or enabling them to live better with their conditions;
- *poor communication between professionals and providers*, exacerbated by the inability to share and transfer data, silo-based working, and embedded cultural behaviours;
- *simultaneous duplication of care* (e.g. repeated tests) and *gaps in care* (e.g. as appointments are missed or medications mismanaged);
- *a poor and disabling experience for the service users*;
- *reduced ability for people to live and manage their needs* effectively; and ultimately;
- *poor system outcomes*, for example, in terms of the inability to prevent unnecessary hospitalisations (Goodwin and Alonso 2014).

A key aspect of integrated care, then, is the ability to effectively coordinate care around people’s needs. What is important to understand is that effective care coordination can be achieved without the need for formal integration of structures

or organisations. Within single providers, integrated care can often be weak unless internal communication or silo-based working has been addressed. As Curry and Ham (2010) demonstrate in their review of the literature, it is the coordination of care at a clinical and service level that matters the most.

While a user-centred definition appears to be the most logical and useful approach to take to define integrated care, it is not for this Handbook to provide the overarching definition of integrated care that should be adopted by all. If the evidence for adoption tells us one thing, it is that there is a requirement for all local stakeholders to come together and agree on their own definition and meaning for integrated care as a means to guide their collective actions. However, in many ways, our overall understanding of the definition of integrated care should be made very simple. Integration (from the Latin *integer*, meaning whole or entire) generally means combining parts so that they work together or form a whole. Care, which can have many meanings, does in this context refer to providing attentive assistance or treatment to people in need. Hence, *integrated care* results when the former (integration) is required to optimise the latter (care) and so is particularly important where fragmentations in care delivery have led to a negative impact on care experiences and outcomes.

The advantage to such a simple definition is that it might help overcome the tendency to focus on structural or organisationally-based solutions, or those that focus purely on integration as a means to create cost efficiencies (which as we will see later in this Handbook might often lead to negative results). Rather, by providing the definition of integrated care with a purpose, so integrated care is given a compelling logic as to its objectives and, therefore, leads to a recognition for how success through integrated care might be judged (Lewis et al. 2010).

In conclusion, integrated care is an approach for individuals or populations where gaps in care, or poor care coordination, leads to an adverse impact on care experiences and care outcomes. Integrated care may be best suited to frail older people, to those living with long-term chronic and mental health illnesses, and to those with medically complex needs or requiring urgent care. However, integrated care should *not* be solely regarded as a response to managing medical problems, and the principles extend to the wider definition of promoting health and wellbeing.

1.4 The Core Dimensions of Integrated Care

One of the key problems to understanding integrated care is its complexity. To support this, there have been a number of different taxonomies developed in order to manage our understanding. Typically, these have examined (after Nolte and McKee 2008; Goodwin and Alonso 2014):

- the *process* of integration (i.e. the mechanisms—both technical and behavioural—required to integrate the work of people and organisations);
- the *degree* or *intensity* of integration (i.e. whether the process involves the ‘full integration’ of health and social care organisations into a new organisational

model or whether the approach supports the creation of non-binding linkages or ties that support better coordination between them);

- the *breadth* of integration (i.e. whether it is fully oriented to: a whole population group; a specific client group—say older people or children; or a specific illness, such as diabetes);
- the *types* of integration (i.e. organisational, professional, cultural, technological);
- the *time span* for integration (i.e. whether it is a ‘life-course’ approach to people over time, or whether focused on specific episodes of care); and
- the *level* at which integration occurs (i.e. macro-, meso- and micro- and even nano- at the point of care with the individual).

Moreover, integrated care appears to have taken a number of key forms, including (after Goodwin and Smith 2012; IJIC no date):

- *Horizontal integration.* Integrated care between health services, social services and other care providers that is usually based on the development of multi-disciplinary teams and/or care networks that support a specific client group (e.g. for older people with complex needs);
- *Vertical integration.* Integrated care across primary, community, hospital and tertiary care services manifest in protocol-driven (best practice) care pathways for people with specific diseases (such as COPD and diabetes) and/or care transitions between hospitals to intermediate and community-based care providers;
- *Sectoral integration.* Integrated care within one sector, for example, combining horizontal and vertical programmes of integrated care within mental health services through multi-professional teams and networks of primary, community and secondary care providers;
- *People-centred integration:* Integrated care between providers and patients and other service users to engage and empower people through health education, shared decision-making, supported self-management, and community engagement; and
- *Whole-system integration:* Integrated care that embraces public health to support both a population-based and person-centred approach to care. This is integrated care at its most ambitious since it focuses on the multiple needs of whole populations, not just to care groups or diseases.

One of the most important issues when adopting integrated care as a service design principle is the extent to which funders and/or care delivery organisations should opt to formally create new structural entities or otherwise seek to coordinate their activities in a less formal network. As discussed above, what really appears to matter is not the organisational solution but the service-level and clinical-level integration that occurs with and around service users. Yet there is evidence to suggest that the more severe the need of the patient, the more appropriate it might be to develop ‘fully integrated’ organisations to manage their complex needs (see Fig. 1.3).

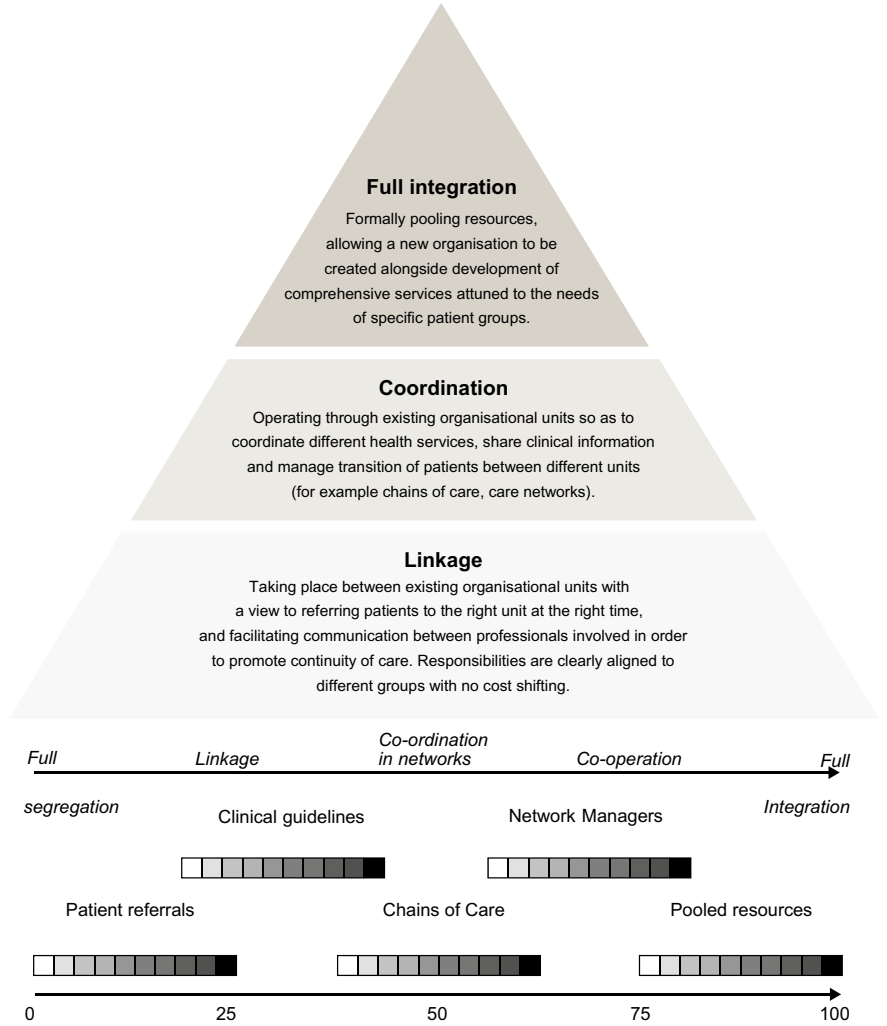


Fig. 1.3 Intensity of integration (Leutz 1999 cited in Shaw et al. 2011, p. 15 and adapted from Ahgren and Axelsson 2005)

Hence, there appears to be a continuum of forms of integrated care from a ‘linkage’ approach (sometimes referred to as ‘virtual’ integration) that might seek to ensure effective information sharing and focus on effective referral practices; to a ‘coordination’ model that might develop more formal connections such as care pathway agreements to enable effective care transitions between service providers; to a ‘fully integrated’ service where new organisational forms, perhaps using pooled budgets, become dedicated to the management of care to defined patient groups or populations (Ahgren and Axelsson 2005).

Table 1.2 Matching client needs with approaches to integrated care (Leutz 1999)

Client needs	Linkage	Coordination	Full integration
Severity	Mild to moderate	Moderate to severe	Moderate to severe
Stability	Stable	Stable	Unstable
Duration	Short to long-term	Short to long-term	Long-term to terminal
Urgency	Routine/non-urgent	Mostly routine	Frequently urgent
Scope of need	Narrow to moderate	Moderate to broad	Broad
Self-direction	Self-directed	Moderate self-directed	Weak self-directed

Moreover, the intensity of the organisational solution to integrated care has been argued to reflect the severity of the needs of the patient or service user. As Table 1.2 demonstrates, full integration is argued to work best when aimed at people with severe, complex and long-term needs. Hence, for a person with lower levels of need, an appropriate response to care integration might focus more on a ‘linkage’ model. This might encourage systems that seek to identify people in local communities with emergent needs (e.g. are at risk of becoming frail and/or having one or more chronic conditions) and support the appropriate follow-up and information sharing. Conversely, for people with high needs, integrated care might require the development of intensive multi-disciplinary care teams, common management structures enabled through pooled funding and shared information systems (Leutz 1999).

The ability to match resources to the needs of population groups, for example, as a means to promote care management to high-risk individuals, has become one of the most well-established approaches to integrated care strategies. Pioneered by Kaiser Permanente in the USA, stratifying populations to their risk profiles (see Fig. 1.4) can enable targeted, community-based and pro-active approaches to care that seeks to prevent unnecessary institutionalisation (Singh and Ham 2006).

However, there is a countervailing argument that suggests that fully integrated systems for people with highly complex needs might not necessarily be an appropriate solution and does not necessarily lead to the better management of their needs (6 P et al. 2006). This is because it can be very difficult to predict the variable demands of the high-risk patient on a day-to-day basis and, as a result, the creation of care management organisations might not have the human and financial resources available to respond effectively (Ross et al. 2012). Recent research on care coordination to people with complex needs suggests that a ‘core team’ is required to support day-to-day needs, but a responsive provider network is also needed to support people when unmanageable complexities in care arise (Goodwin et al. 2013, 2014). One of the most recent developments in the discussion of integrated care is evolving ecosystems. There are several ways of defining ecosystems. One is the understanding based on complex adaptive systems and existing integrated care networks (see Chap. 35 in this book and Dessers and Mohr 2019). Another is along the lines of Amazon, which developed from an online book seller to a whole-sale retailer and a one-stop shop (Davidson et al. 2015; Jacobides et al. 2018).



Fig. 1.4 ‘Kaiser Triangle’: deploying different strategies for integrated care according to the risk profiles of populations (adapted from Singh and Ham 2006)

1.5 The Building Blocks of Integrated Care

Many frameworks have been developed to understand the key elements, or building blocks, that comprise a successful integrated care programme. One of the most influential frameworks, as described above, has been the CCM that set out the design of integrated chronic care initiatives to improve quality and outcomes. The CCM was developed from a Cochrane systematic review of factors in recognition of the failures of health systems in meeting the needs of people with chronic illnesses since they remain largely built on acute, episodic models of care rather than care that focuses on more longitudinal, preventative, community-based and integrated approaches. The CCM aimed to provide a comprehensive framework for the organisation of health care in order to improve outcomes for people with chronic conditions (see Box 1.2).

Box 1.2 The Six Interrelated Components of the Chronic Care Model

1. self-management support,
 - a. patient education
 - b. patient activation/psychosocial support
 - c. self-management assessment
 - d. self-management resources and tools
 - e. collaborative decision-making with patients
 - f. guidelines/education

2. decision support,
 - a. decision-support tools and guidelines
 - b. provider education
 - c. expert consultation support
3. delivery system redesign,
 - a. care management roles
 - b. team practice
 - c. care coo-ordination and care coordinators
 - d. pro-active follow-up
 - e. planned visits
4. clinical information systems,
 - a. patient registries
 - b. information use for care management
 - c. feedback on performance data
5. community resources
 - a. for patients
 - b. for community
6. health system (support)
 - a. leadership
 - b. provider engagement
 - c. system to spread innovation and improvements

Further revised since to include: cultural competency; patient safety; care coordination; community policies; and case management.

Source: Wagner et al. (1999).

Several variations of the CCM, including the *Expanded Chronic Care Model* and the *Innovative Care for Chronic Conditions*, have focused on the importance of the broad determinants of health (Barr et al. 2003; WHO 2002). They stress the importance of coordinated interventions that cut across the primary, secondary and tertiary levels of care and beyond the boundaries of the healthcare system to cover issues such as public health (i.e. population health promotion, prevention, screening and early detection), management of diagnosed cases, rehabilitation and palliative care).

For example, the *Expanded Chronic Care Model* identified a number of additional domains to the original CCM including: community resources and policies (such as healthy public policy, a focus on influencing the socio-determinants of ill-health through the living environment and strengthening community action); self-management support; decision-support to professionals through evidence-based guidelines; a focus on quality of life and holistic needs rather than just clinical outcomes; and the importance of data systems that integrate information across sectors (Barr et al. 2003).

The *Innovative Care for Chronic Conditions*, developed by the WHO as part of a ‘road map’ for countries and their health systems to deal with the rising burden of chronic illness, placed a specific premium on prevention through ‘productive partnerships’ between patients and families, community partners and healthcare teams to create informed, prepared and motivated communities. Eight strategies for action were presented to support the model become reality (WHO 2002; see Fig. 1.5). Other framework developments have included the *patient-centred medical home (PCMH)* that represents an evidence-based model of enhanced primary care developed in the USA that can provide care which is accessible, continuous, comprehensive and coordinated and delivered in the context of family and community (National Committee for Quality Assurance 2016). PCMH evolved as a response in how to manage *all* patients in a particular community, rather than those with chronic illness as in CCM, and was particularly targeted at children and adolescents and other people requiring more holistic care and treatment. PCMH was piloted as an approach within Medicare and Medicaid insurance programmes,



Fig. 1.5 Innovative care for chronic conditions framework (adapted from WHO 2002)

including the creation of new payments and incentives for group practices that meet the core criteria associated with being designated as a PCMH. The key domains of the approach include: having a personal physician (continuity of care); physician-directed medical practice; whole person orientation; care that is coordinated and/or integrated around a person's individual needs; quality and safety targets; and enhanced access (to primary care).

The frameworks and models for care systems described above have primarily evolved from the USA and been confined in their thinking to *within* health systems and not sought to identify the wider range of actions that decision-makers would need to adopt to enable integrated care to be adopted. One knowledge synthesis conducted in Canada, however, that sought to address this was able to develop 'ten principles of successful integrated systems' (Suter et al. 2007) from which some care systems in Canada derived a simple scorecard to reflect on their capabilities (see Box 1.3). The research was updated and validated through a series of Delphi exercises, and a revised version was published in 2017 (Suter et al. 2017).

Box 1.3 Ten Principles for Successfully Integrated Systems (Suter et al. 2007)

1. *Care across the continuum.* Recognising the importance of providing seamless health care despite the multiple points of access
2. *Patient focus.* Encouraging active participation by the patients, families or informal caregivers while focusing on population-based needs' assessment
3. *Geographic coverage and rostering.* Rostering to maximise accessibility and minimise duplications
4. *Standardised care delivery through inter-professional teams.* Using provider-developed and evidence-based clinical care guidelines and protocols
5. *Performance measurement.* Evaluating the process of integration and measuring system, provider, and patient outcomes
6. *Appropriate information technology and communication.* Collecting data through electronic patient records systems to effectively track utilisation and outcomes
7. *Organisational culture and leadership.* Sharing a vision of an integrated healthcare delivery system through strong leadership and cohesion
8. *Physician engagement.* Integrating physicians, particularly primary care physicians, by a variety of methods such as compensation mechanisms, financial incentives and non-financial ways of improving quality of life
9. *Strong governance structure.* Implementing a strong governance structure that includes community and physician representatives;
10. *Sound financial management.* Encouraging fiscal responsibility.

Of the range of interpretations and conceptual frameworks through which to understand and study the complexities of integrated care, it is the comparatively recent work by Valentijn et al. that provides one of the more elegant approaches (Valentijn 2016; Valentijn et al. 2013 and see Fig. 1.6). By placing people-focused and population-based coordinated care as the guiding principle or objective of integration, their research describes the range of different integration processes at the macro-level (system integration), meso-level (organisational and professional integration) and micro-level (clinical, service and personal integration). Functional integration (e.g. communication and the use of ICT) sits alongside normative integration (e.g. shared cultural values) to ensure effective connectivity between the functioning of the integrated care system between various levels. Hence, information and communication is regarded as a key transversal issue with a role as a ‘connector’ of processes that has the dual quality of both being the ‘glue’ through which people and organisations come together to provide more integrated services, but also the ‘grease’ in making these relationships dynamic through creating effective channels of communication and data sharing.

Valentijn et al.’s *Rainbow Model* of integrated care (Fig. 1.6) is a very useful way to conceptualise the inter-relationships among different dimensions of integrated care though it does drive a ‘process-driven’ rather than ‘user-centred’ understanding. In a final taxonomy of integrated care elements positively associated with each of the different levels (see Box 1.4), the research did not focus on core issues related to person-centred care nor on the wider issues that other frameworks had identified regarding the ability to tackle the socio-determinants of ill-health or integrate public health approaches into integrated care strategies. This is not to

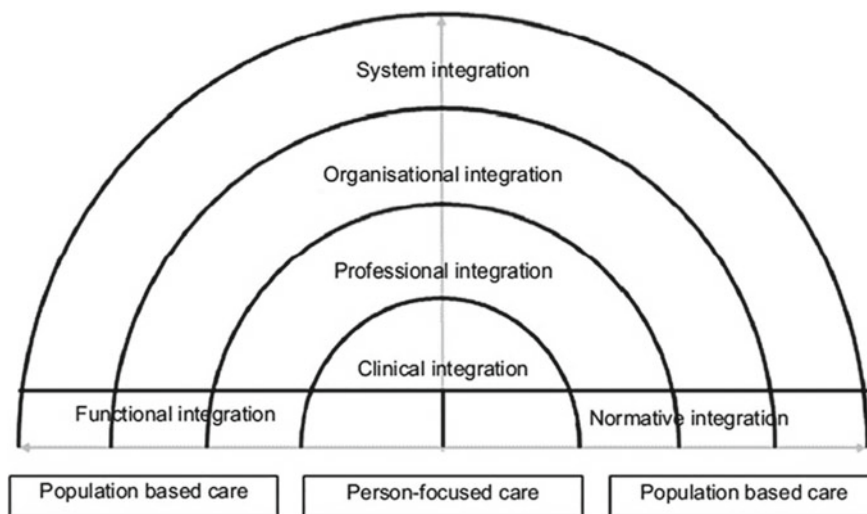


Fig. 1.6 Rainbow model of integrated care (after Valentijn et al. 2013)

criticise the *Rainbow Model* but demonstrates the problems in developing a generic template or tool through which to judge the key success factors across what is a complex service innovation. This leads to the recognition that the concept of integrated care should be seen as so much more than the sum of complex organisational and systemic processes but be regarded as a fundamental design principle in the future of care systems (Goodwin 2013a).

Box 1.4 The Rainbow Model of Integrated Care: Final Taxonomy Summary (from Valentijn 2016).

<i>Clinical integration:</i> case management, continuity of care, multi-disciplinary care plans, supportive relationship with client	<i>System integration:</i> aligned regulatory frameworks to support care coordination and team work
<i>Professional integration:</i> inter-professional education, inter-disciplinary teams	<i>Functional integration:</i> shared information systems; collective learning and joint research; regular feedback on performance measures
<i>Organisational integration:</i> shared governance and accountability; shared strategy; trust	<i>Normative integration:</i> shared vision; reciprocity of behaviour; mutual gain; visionary leadership; distributed leadership; shared norms and values

Most recently, the World Health Organisation has published a series of papers examining the transformational processes necessary to achieve people-centred and integrated health services delivery. WHO Europe, for example, has published its European Framework for Action on Integrated Health Services Delivery (WHO Regional Office for Europe 2016). The Framework provides an ‘implementation package’ designed for people and institutions in political and technical roles responsible for integrated care policy and practice.

In parallel to this, and based on its own examination of the evidence internationally, the WHO at the global level has since published its *Framework on Integrated People-Centred Services* (WHO 2016). Having been ratified by WHO’s General Assembly in May 2016, it implies that all WHO member states (including across the EU) have signed up to the formal commitment to implement integrated care. In terms of implementation, the Framework sets out five interwoven strategies that need to be implemented for health service delivery to become more integrated and people-centred: empowering and engaging people and communities;

strengthening governance and accountability; reorienting the model of care; coordinating services within and across sectors; and creating an enabling environment.

1.6 Conclusions

Without the full alignment of political, regulatory, organisational and professional support for the goals of integrated care, a significant degree of local leadership and commitment is needed at a clinical and service level to make change happen. This does not appear to be a sustainable proposition for the long-term future of integrated care, nor will it allow the widespread uptake of these approaches. Perhaps all countries need to re-evaluate and recalibrate their health and social care systems such that local service innovations can be supported to integrate services that can better meet the growing needs of [older] people with complex and multiple conditions (Goodwin et al. 2014, p. 22).

Integrated care is difficult to define and understand since it represents a complex service innovation in the way health and care services should be redesigned around people's needs. Consequently, integrated care has come to mean different things to different people and the resulting conceptual 'soup' has often acted as a barrier when it comes to developing commonly understood strategies to support implementation and change. However, as this chapter has attempted to outline, there are three distinct dimensions to what integrated care means in practice:

- First, integrated care is a necessary response to overcome fragmentations in care delivery where this adversely impacts on the ability to coordinate care effectively around people's needs and so leads to sub-optimal results in terms of people's care experiences and outcomes.
- Second, integrated care represents an approach to improve the quality and cost-effectiveness of care by ensuring that services are well coordinated around people's needs. Integrated care is by definition, therefore, both 'people-centred' and 'population-oriented'.
- Third, it is this people-centred focus that becomes the organising principle for integrated care as a service innovation, whether this be related to individual patients, the carer/family or the wider community to which they belong.

However, our understanding of integrated care, its complexities, its components and the ways to implement it remains an emerging scientific discipline. There is a significant and emerging body of knowledge that helps us understand and appreciate the building blocks that need to be put in place for the effective development of integrated care in policy and practice. Yet, as the next chapters in this Handbook make clear, what appears to be more difficult is our understanding of the impact of integrated care programmes and the relationship between the component parts of an integrated care solution that contributes to improving outcomes.

It has been observed that the implementation science to integrated care remains weak (Goodwin 2013b). In part, this is a reflection on how many integrated care programmes are immature, often ill-defined and lacking in focus. Much still needs

to be done through research to broaden our conceptual and empirical understanding, but in a way that pro-actively supports adoption to meet the ‘Quadruple Aim’ goals that have been adopted as the core hypothesis behind the integrated care movement.

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Refocussing Care—What Does People-Centredness Mean?

2

K. Viktoria Stein and Volker Amelung

2.1 Introduction

From the very beginning, integrated care set out to transform care systems and shift the focus from organisations and structures to patients and communities. The IOM (2001) defined patient-centredness as one of the six elements of high-quality health care, and the WHO has emphasised the importance of responsiveness, patient- and people-centredness and community involvement in several reports over the last 2 decades, starting with the World Health Report 2000 (e.g. WHO 2000, 2007, 2015, 2016; WHO and UNICEF 2018). But after decades of putting theory into practice, the inclusion of patients, families and communities on all levels and in all aspects of care is still far from the norm and often an afterthought (Goodwin 2016; Stoop et al. 2019). ‘We can’t include people yet! We don’t know ourselves what we want to do, so how could we invite others to join the discussion?’ This argument is frequently used by professionals, managers and decision-makers when answering the question whether they had already reached out to the people, who should ‘profit’ from integrated care. The prevailing culture is still that we do integrated care TO people and not WITH them. The COVID-19 pandemic is only the latest crisis showcasing the abyss between formal and informal care, community resilience and political ineptitude, when it comes to making sure that people receive the care and support they need, when they need it and where they need it. This chapter will frame the

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concept at the heart of integrated care and outline the many possibilities to involve patients, families and communities in the design, implementation and delivery of integrated care.

2.2 Theoretical Underpinnings

As outlined in Chap. 1 of this Handbook, integrated care aspires to address the ‘Quadruple Aim’ (Bodenheimer and Sinsky 2014) of health systems by improving coordination, collaboration and management of health and care systems. At the heart of the movement lies the rediscovery and development of the principle of a healthy mind, which lives in a healthy body, and was first formulated in Ancient Greece and Rome some 3000 years ago. In modern times, this was epitomised by WHO’s definition of health as ‘a state of complete physical, mental and social wellbeing, and not merely the absence of disease’ (WHO 1946). In clinical-practical terms, the bio-psycho-social model developed by Engel (1977) tried to introduce this holistic understanding of health and well-being, which focusses on the needs of the whole person, and not on the isolated treatment of a symptom. Both concepts emphasise the relationship between body and mind of an individual in the context of their social environment in order to successfully treat and support a person. The concept of salutogenesis was borne out of these reflections. Underneath this umbrella term, very different theories are subsumed, but which all deal with the strengthening and empowerment of the person. Some of these concepts specifically address the importance of social connectedness and being a member of a healthy community in order to be able to fulfil ones potential and feel truly well (Fig. 2.1).

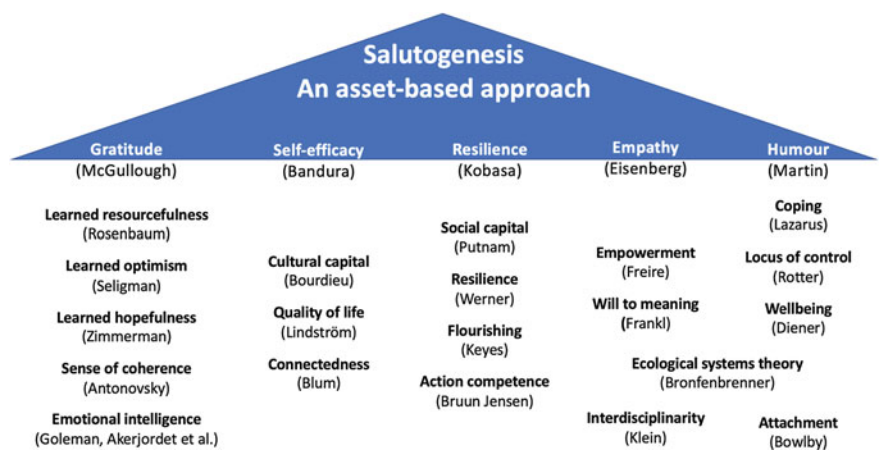


Fig. 2.1 Concepts and theories of salutogenesis. *Source* Own illustration, based on Lindström and Eriksson (2010) and Eriksson and Lindström (2010)

The theories represent so diverse fields as economics (e.g. social capital), philosophy (e.g. cultural capital) or psychology (e.g. will to meaning), but they all serve a common purpose: in contrast to pathogenesis, which is still prevalent in our health systems today and which deals with the development and combat of illness, salutogenesis looks at the development and maintenance of health and well-being. As such, it is at the core of what people-centredness is all about.

This understanding of health and well-being still represents a major paradigm shift, which needs to happen on all levels of the system. People and civil society need to take a more active part in the decision-making process about their own health, professionals need to let go of their paternalistic treatment of patients and families, and organisations and systems need to change the funding, regulatory and monitoring frameworks to achieve outcomes important to people and communities (Horne et al. 2013).

2.3 What Does ‘People-Centred’ Mean?

‘The people-centred approach meets these broader challenges by recognising 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 healthcare organisations 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).

As with most other concepts associated with integrated care, there are a plethora of terms used synonymously and simultaneously for those receiving services (Miller et al. 2016; The Health Foundation 2016). Depending on the perspective and the system, the terms ‘patients’, ‘service users’, ‘clients’, ‘consumers’ or ‘persons with lived experience’ may be used. These terms come with different connotations, but in effect all talk about people who access health and care services from a variety of service providers and organisations (Miller et al. 2016). Similarly, integrated care has been described as being ‘patient-centred’, ‘person-centred’, ‘people-centred’, and more recently, ‘people-powered’ or ‘people-driven’. These terms can be seen as representing a continuum of inclusivity and a growing understanding of who needs to be involved and to what degree in integrated care, where ‘patient-centred’ signifies the first, still clinically driven, realisation that individual patients need to be involved in clinical decision-making about their health and care. On the other end of the spectrum, recent developments reflect the broader demand of communities and populations to take active part in the design and policy-making about public services and systems. ‘People-powered’ and ‘people-driven’ thus represent a 180° shift in perspective, putting people and communities in the driver’s seat of public policies (WHO 2007; Ferrer 2015; Horne et al. 2013; Thompson 2019).

Box 1. Some Denitions

Patient-centred care means ‘providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions’ (IOM 2001; Gerteis et al. 1993).

Person-centred care ‘depends on the needs, circumstances and preferences of the individual receiving care’ (The Health Foundation 2016).

People-centred care is ‘an approach to care that consciously adopts the perspectives of individuals, families and communities, and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways’ (WHO 2015).

‘The *People Powered Health* approach draws on the expertise and commitment of the people it serves, and supports them to change behaviours and create social networks that improve health’ (Horne et al. 2013).

People-driven care is based on people’s needs and their strengths. People-driven care centres on the ability to engage and empower people to take control of the factors that influence their health and wellbeing, including addressing social determinants of health’ (Based on Marmot et al. 2008).

These definitions give an overview of what can be understood by the different terms, but it should be recognised that there is no universally accepted definition for any of them. As mentioned above, they represent a fluid, but continuous evolution of how far reaching the involvement of individuals and communities may go and how many aspects of life and public administration should and need to be included. The commonalities in all these concepts, approaches and definitions echo the principles of integrated care in general: it is about changing perspectives, taking a holistic and inclusive approach to health and care, building trusted relationships and respecting each other as equal partners in care (Stoop et al. 2020; Ferrer 2015; Miller et al. 2016; The Health Foundation 2016).

As it is well established by now, that 90% of our health and well-being are influenced by factors outside the clinical–medical realm, whether it be personal life choices, the built environment and infrastructure or education, the need for people-centred policy-making and system design is ever more pressing (Gnadinger 2014; Hood et al. 2016; Kindig 2008). However, while all these terms essentially call for the same thing, they are not synonymous, and thus it is important to determine, at what level involvement and engagement of people happen and what the purpose of it is. Is it the focus on individual patients and families to support their day-to-day care, or is it to include civil society representatives in the management of an integrated care system? As always, it is necessary to clearly identify the purpose of involvement and engagement and the roles, to determine which tools are adequate to achieve people-centredness and whom one needs to involve (Miller et al. 2016). Arnstein’s ‘Ladder of Participation’ (1969) established a clear

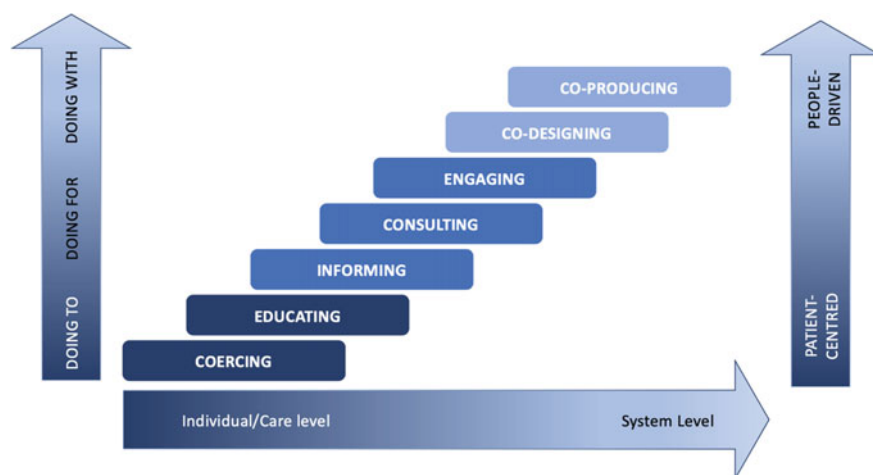


Fig. 2.2 Ladder of participation for integrated care. *Source* Own illustration, based on and adapted from Arnstein (1969)

hierarchy from ‘doing to’ to ‘doing with’, which is still very useful in distinguishing whether the policies, strategies and activities designed and implemented in the guise of integrated people-centred service delivery, actually are what they claim to be. Combining it with the terms defined in Box 1 illustrates the intensity of involvement needed (Fig. 2.2).

Many systems have already come some way from the paternalistic, coercing attitude towards patients and families, implementing some measures of shared decision-making and shared care planning, supporting self-management and involving informal caregivers, but a truly people-centred or people-driven system will need a more fundamental change than these local, stepwise and half-hearted efforts of recognising the growing need and demand for a more inclusive health and care system on all levels.

2.4 Strategies and Instruments to Support People-Centred Services and Systems

As outlined in the introduction of this book, integrated care aims at improving the quality of life, quality of care and satisfaction of people and communities with their services. Thus, people-centredness can be seen as fulfilling a dual purpose: (a) it can be an end in itself, i.e. in the democratic sense of having civil society representation throughout the system (people-powered, people-driven care), or (b) it can be a means to an end, i.e. by involving people and families in their own care, this will better meet their needs and lead to better outcomes (patient-centred, person-centred,

people-centred care) (Miller et al. 2016). These different aspects, roles and perspectives are reflected in the definitions and frameworks put forward over the last two decades, but again, a common thread can be made out through all of them. Again, Box 2 only represents examples of definitions and does not purport to represent the ultimate versions.

Box 2. Denitions for Engaging Individuals and Communities

People empowerment refers to ‘the process by which people develop their intrinsic capabilities to increase control over the factors, decisions and actions that affect their health and care and the process of gaining power externally over them’ (Ferrer 2015).

People engagement is ‘the process by which people increase their degree of active involvement in caring for themselves and in shaping their health determinants’ (Ferrer 2015).

Co-design enables people to make a creative contribution in the formulation and solution of a health-related challenge. The approach focusses on addressing people’s needs rather than those of institutions. It goes beyond consultation since it seeks to build equal collaboration between all those affected by, or seeking to resolve, such challenges. A key tenet of co-design is that people are ‘experts of their own experience’ and so the process involves the active facilitation of engagement between people to communicate, share insights and test out new ideas (IJIC 2020).

Co-production represents care and support that is delivered in an equal and reciprocal relationship between clinical and non-clinical professionals, individuals using care services, their families and the communities to which they belong. Co-production implies a long-term relationship between people, providers and healthcare systems where information, decision-making and service delivery become shared (IJIC 2020).

Another way of thinking through the different involvement and engagement activities to achieve people-centred services and systems is to distinguish between improving health and well-being for individuals or communities versus designing and implementing policies with individuals or populations. Ferrer (2015) compiled a comprehensive set of tools, strategies and evidence to achieve these different levels of engagement and empowerment, from the individual patient-centred approaches of self-management and shared care planning, to population and system-level public benchmarking of system performance, as evidenced by the example of the state of Vermont. One reason why a sustainable and system-wide shift to people-centred thinking and working has not happened yet is the fact that the implementation of self-management does not stop at the interface of patient/family and professional, i.e. the micro-level. It needs to be supported by a culture and strategy of shared governance and management on the meso-level and

lead by supportive and shared values and principles on the system level (see Table 2.1). Only then will the efforts on the micro-level not evaporate when dedicated professionals run into barriers, e.g. of information sharing or patients face the problems of unconnected health and social services.

Along the same lines, Ferrer (2015), in her seminal report for the WHO Regional Office for Europe, outlined four key strategies for patient engagement and four key strategies for population empowerment. For each strategy, she identified tools and examples for patients and families, professionals and policy-makers, as well as for supporting implementation, and provided the overwhelmingly positive evidence for all of them.

Tables 2.1 and 2.2 give cursory examples of how people-centredness may be realised on all levels, but it also highlights the subtle differences in understanding of what engagement, empowerment and co-design mean. Ultimately, it is not important to agree on the definitions, but on the actions, which need to be taken in order to move from a disease focussed to people-driven system of health and care. And there is clear evidence available that a more engaged and actively involved population, with adequate health literacy levels, along with a better educated workforce experiences better health and well-being outcomes and uses less resources than a passive population (Ferrer 2015).

Underlying these discussions is also an ethical question of rights and responsibilities. If applied correctly, shared decision-making and care planning will enable individuals and families to articulate what they can and cannot do, e.g. through goal-oriented care. Integrated people-centred services will also support marginalised groups to receive access to the necessary care services and help professionals share responsibilities across services. On the system level, this calls for clear regulatory frameworks and the enforcement of the human right to health and health care, among other things (Cohen and Ezer 2013; Gruskin et al. 2007).

Table 2.1 Selected activities of involvement to achieve people-centred systems

Micro (care or service integration)	Meso (professional and organisational integration)	Macro (system integration)
Self-management	Shared governance and management	Establishing values, principles and strategies
Evaluation, e.g. feedback	Quality improvement and management, e.g. lay advisory boards	Transparent monitoring and benchmarking systems
Patient and family researchers	Evidence-based practice and integrated care guidelines	Evidence-based policy making
Shared decision-making and care planning	Interdisciplinary teams including informal care givers	Civil society representation in decision-making bodies
Co-production of services	Co-design of services and organisations	Co-creation of integrated care systems

Source Adapted from Miller et al. (2016)

Table 2.2 Examples of strategies and tools for patient engagement and population empowerment

Strategies for patient engagement	For patients	For professionals	For policymakers	For implementation
Self-management	Raising awareness about available resources, e.g. apps	Identifying and tailoring self-management support according to health literacy levels, e.g. through standardised questions	Raising awareness and understanding of the importance of self-management, e.g. through public campaigns	Creating platforms for knowledge exchange, e.g. the Self-Management Network Scotland
Shared decision-making	Decision aids to support patients in considering why one option is better than other and what is important for them about their decision, e.g. the Ottawa Personal Decision Guide and the Guide for Two	Education and training: when health professionals participate in education, they are more likely to use patient decision aids and share decision-making with patients (Legare et al. 2010)	Developing frameworks and strategies to support shared decision-making, e.g. the Ottawa Decision Support Framework	Support research projects and knowledge exchange, e.g. monitoring and evaluation
Peer-2-peer support	Setting up and training peer support networks, e.g. in the NUKA system (Alaska)	Connecting patients with peer support networks	Supporting the establishment of community health workers as promoted by WHO	Joining the Global Network of Peer Support
Supporting patients and families	Respite care for carers	Including informal caregivers in the decision and planning of care	Improving support for informal caregivers, e.g. through paid leave	Using carer assessments as part of an evaluation and monitoring strategy
<i>Strategies for population empowerment</i>				
Protecting peoples' rights and fostering shared responsibilities	Active involvement in citizen's panels or lay advisory boards	Training to understand the implications of patient's rights and how to address them in every day practice	Mandating people representation with voting rights on all levels of the system	Using a health-related human rights impact assessment for service and system design

(continued)

Table 2.2 (continued)

Strategies for patient engagement	For patients	For professionals	For policymakers	For implementation
Enabling informed choice	Using consumer reports and healthy choice guides	Taking time to explain alternative choices and resources available	Supplying culturally adapted guidebooks	Monitoring and evaluation frameworks
Strengthening health literacy	Developing skills for health and attending educational programmes	Improving patient–provider communication and simplifying language and tools	Raising awareness and developing targeted campaigns and programmes	Using implementation framework, toolkits and strategies, such as provided by Health Literacy Europe
Supporting community development	Getting involved in community groups or volunteering	Using communities as assets and engaging with local support networks	Developing coalition and community coalition-driven interventions	Using community implementation programmes and assessment, e.g. the CDC Community Health Assessment and Group Evaluation (CHANGE)

Source Adapted from Ferrer (2015)

2.5 Prerequisites for People-Centred Services and Systems

Throughout this chapter, barriers and challenges have been mentioned, which still impede the radical cultural and systemic change necessary to implement integrated people-centred systems at scale. Given how long the interplay of body, mind and social environment has already been recognised as essential for the health and well-being of people, it is at first glance astonishing that so little has changed in our systems thus far. However, upon closer scrutiny, the shift from patho- to salutogenesis represents a profound paradigm shift, which touches at the cultural, financial and structural core of our systems (see various chapters in this Handbook). While politicians, professionals and civil society may concur that such a shift is necessary, this would necessitate painful behaviour changes for all of us (WHO 2007; Horne et al. 2013; TransForm 2019):

- We need to change what and how we measure and value health and well-being. The current systems of clinically driven, process-oriented indicators are inadequate to capture the complex interrelating factors the influence health and well-being (see chapters Nolte and Suter).
- We need to change how we pay for services, as episodic, disease-related payments to not reflect the catalogue of services and processes needed to treat complex and chronic conditions, or incentivise healthy behaviour (change) (see chapters Tsiachristas).
- We need to change the dominant culture in our workforce and organisations, to reflect the interdisciplinary, cross-sectoral and holistic values and principles, which found the basis of integrated people-centred care systems (see chapters Goodwin, Stein, Miller and Busetto).

In Part II of this book, stories of such changes illustrate that it is possible, albeit locally or piecemeal. The journey from static disease repair system to complex adaptive health system is long and arduous, and it needs a lot of personal courage and dedication to get it started. There is still no health and care system in the world, which can claim to be truly people-centred, and it may be that it needs another 50 years for this concept to gestate and become ingrained in our structures, processes and culture. After all, it took the WHO definition for health that long to find a concept, which would take its aspiration seriously.

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Evidence Supporting Integrated Care

3

Ellen Nolte

3.1 Introduction

An ageing population coupled with a rising burden of chronic diseases, growing user expectations and technological advances challenge health care delivery in many countries. Against a backdrop of increasing financial constraints, this creates a pressing need for more efficient use of resources. There is increasing concern about health systems' continued focus on acute, episodic illness with their dependence on hospital-based care delivery. Apart from being very costly, there are questions about the suitability and efficiency of such services in the light of the changing disease burden (Rechel et al. 2009) and the rising proportion of people with multiple health problems (Barnett et al. 2012). Chronic conditions create a spectrum of long-term and fluctuating needs. In combination with increasing frailty at old age, these conditions require the development of delivery systems that bring together a range of professionals and skills from both the cure and care sectors, as well as active service user engagement (Holman and Lorig 2000; Nolte and McKee 2008a).

Yet, service delivery has developed in ways that have tended to fragment care both within and between sectors. For example, structural and financial barriers dividing providers at the primary and secondary care and at the health and social care interface, distinct organisational and professional cultures, and differences in terms of governance and accountability all contribute to care fragmentation (Glasby et al. 2006). As a consequence, people typically receive care from many different providers, often in different settings or institutions; they are frequently called upon to monitor, coordinate, or carry out their own care plan, often with limited guidance

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on how to do so (House of Commons Health Committee 2014; Nolte et al. 2008). Failure to better coordinate services along the care continuum may result in sub-optimal outcomes, such as potentially preventable hospitalisations, medication errors, and other adverse events (Vogeli et al. 2007).

It is against this background that, globally, systems have set out to explore new approaches to health care delivery that can bridge the boundaries between professions, providers, and institutions and so provide appropriate support to people with long-standing health and care needs (Nolte et al. 2008; WHO Regional Office for Europe 2016; World Health Organisation 2015). At the policy level, countries have sought to create regulatory and policy frameworks to promote approaches that better integrate care and improve coordination between sectors and levels of care. This often occurs alongside efforts to shift specialist services from hospital into the community as a means to increase the accessibility of services and the responsiveness of the system, and, potentially, reduce costs (Ettelt et al. 2006; Nolte et al. 2014; Winpenny et al. 2016). In Europe, this development has been supported by the 2011 European Council Conclusion recommending countries introduce innovative approaches and models of health care to move towards more integrated care systems, enhance equitable access to high quality care, and reduce inequalities (Council of the European Union 2011).

The move to more integrated care systems is often associated with high expectations and a goal of increasing the effectiveness, efficiency, and sustainability of service delivery more broadly. This chapter provides an overview of available evidence supporting integrated care. We begin by briefly describing conceptualisations of integrated care against which to assess the evidence, followed by an overview of the literature that examines the impacts of integrated care. We then discuss some of the key challenges of interpreting the existing evidence base and the extent to which it permits drawing robust conclusions on the effects of integrated care approaches on various outcomes. We close with a set of overarching observations.

3.2 Conceptualising Integrated Care

Depending on the context, strategies to integrate care are sometimes driven by a need to contain cost, sometimes by the need to improve care, and often by both. Central to the development of integrated care is an expectation that it might support achievement of the ‘Triple Aim’ of a simultaneous focus on improving health outcomes, enhancing patient care experience, and reducing the per capita costs of care for populations (Berwick et al. 2008). Available evidence points to a positive impact of integrated care programmes on the quality of patient care and on selected outcomes (Martinez-Gonzalez et al. 2014; Ouwens et al. 2005). However, the effectiveness and consequences of different forms of care integration, including their economic impacts, remain uncertain (Nolte and Pitchforth 2014). This is in part because of the lack of a common understanding of what is being referred to as

‘integrated care’, as well as inconsistencies in describing component approaches and interventions (Martinez-Gonzalez et al. 2014; Nolte and Pitchforth 2014; Ouwens et al. 2005). This section provides a summary of ways to think about integrated care; a detailed review of relevant conceptualisations is presented in Chap. 1.

Integrated care is a concept that has been widely used in many ways by different scholars and in different health systems (Nolte and McKee 2008b). Traditionally, it has been discussed in the health and social care fields, with reference to linking the cure and care sectors (Kodner and Spreeuwenberg 2002). Some authors also suggest linking in broader human services systems such as education and housing in order to improve outcomes (Leutz 1999). The application of the concept of integrated care to health and social care is not clear cut, however, and different conceptualisations have been put forward emphasising, for example, the health care perspective (‘a concept bringing together inputs, delivery, management, and organisation of services related to diagnosis, treatment, care, rehabilitation, and health promotion’ (p. 7) (Groene and Garcia-Barbero 2001), or interpreting integration in terms of financing and delivery functions in the context of managed care (Ovretveit 1998; Shortell et al. 1994).

The common denominator of integrated care concepts and approaches is their primary aim of improving outcomes for, traditionally, frail older people, and other population groups with diverse and complex needs who require assistance with activities of daily living (Nolte and McKee 2008b). It is important, however, to recognise that integration is a much broader concept that applies to many other areas such as urgent care, maternity and child health care, and public health, among others. A common element is the notion that integrated care should be centred on the needs of service users, their families, and the communities to which they belong (Shaw et al. 2011). Lewis et al. (2010) highlighted that a user-centred vision for care delivery is more likely to overcome the tendency to opt for structural or organisation-based solutions, and it also provides a compelling logic regarding the objectives for integrated care and how success might be evaluated.

Systematic understanding of the evidence of the impacts of integrated care has long been hampered by the absence of a ‘sound paradigm through which to examine the process’ (p. 311) (Goodwin et al. 2004), and it has only been more recently that more formal analytical frameworks have been proposed (Minkman et al. 2013; Valentijn et al. 2013; van der Klauw et al. 2014). For example, in an attempt to develop a typology of integration in health and social care that enables systematic assessment of the structures and processes involved, their prerequisites, and their effects on service organisation, delivery, and outcomes, analysts have identified different dimensions of integration. The most commonly used dimensions differentiate the *type*, the *breadth*, the *degree*, and the *process* of integration (Nolte and McKee 2008b). Valentijn et al. (2013) brought these different ways of conceptualising integration together in the form of the Rainbow Model of Integrated Care, which sees integrated care as a person-focused and population-based care approach across the care continuum. In the model, integration occurs at the micro (clinical integration), meso (professional and organisational integration), and macro

(system integration) levels, along with functional and normative integration linking the different levels (see Chap. 1) (Valentijn et al. 2013). It is important to recognise that the process of integration typically requires simultaneous action at the different levels and across different functions, which develop in distinct phases (Minkman 2011). Thus, care integration is not likely to follow a single path and variations will be inevitable.

3.3 The Evidence Supporting Integrated Care

There is now a series of reviews, and reviews of reviews, of the published and grey literature on integrated care models or strategies for people with (specific) chronic conditions (Busetto et al. 2016; Kruis et al. 2013; Martinez-Gonzalez et al. 2014; Ouwers et al. 2005), those with mental health co-morbidity (Lemmens et al. 2016; Rodgers et al. 2016), or for broader population groups (Nolte and Pitchforth 2014). Reviews typically consider a range of approaches that can be subsumed under the heading of integrated care, such as collaborative care, case management, care coordination, or disease management. Indeed, in a review of systematic reviews by Ouwers et al. (2005), which sought to assess the effectiveness, definitions, and components of integrated care programmes for chronically ill patients, the majority of the studies assessed disease management programmes (see Chap. 24) (Ouwers et al. 2005). Similarly, in a meta-review of integrated care programmes for adults with chronic conditions, two-thirds of included studies were reviews of disease management interventions (Martinez-Gonzalez et al. 2014).

Both reviews found evidence of beneficial effects for some outcomes, such as functional health status, clinical outcomes, patient satisfaction, and quality of life. Frequently, there was evidence of a positive trend only, rather than of statistically significant improvements (Martinez-Gonzalez et al. 2014; Ouwers et al. 2005). Evidence of impacts on mortality tended to be mixed. There was also evidence of reduced health care utilisation but again observed trends were often not statistically significant. Evidence of beneficial impacts of integrated care programmes on costs tended to be weak. Based on these observations, review authors concluded that integrated care programmes can lead to improvements in the quality of care and in selected health and resource use outcomes. At the same time, authors also reported a lack of precision among reviewed studies in describing programmes, with variation in definitions and components of care analysed, which made it difficult to arrive at overarching conclusions about the ‘best approach’. Indeed, as Ouwers et al. (2005) noted, such heterogeneity might lead to inappropriate conclusions about programme effectiveness and the application of findings.

This raises the question about the usefulness of seeking to assess the effectiveness of integrated care as such and, more specifically, whether the concept lends itself to evaluation in a way that would allow for the generation of definitive evidence given its complex and polymorphous nature. Indeed, if integrated care is seen as a means to improve outcomes by overcoming issues of fragmentation

through linkage or coordination of services of different providers along the continuum of care, related initiatives will have to be targeted to the needs of a given population, which in turn will be highly context-dependent. Therefore, while it may not be possible to generate clear-cut evidence as to the effectiveness of integrated care as a whole, there is potential for transferable lessons to be learned across different studies to identify core elements that will support better outcomes.

Such an approach was taken in the World Health Organisation's global strategy on people-centred and integrated health services. Published in 2015, work presented in support of the strategy focused on the evidence of effects of interventions and approaches within each of five key strategic directions (World Health Organisation 2015). These strategic directions were: empowering and engaging people, strengthening governance and accountability, reorienting the model of care, coordinating services, and creating an enabling environment. For example, under the heading of 'empowering and engaging people', the most common and effective interventions were identified to be in the areas of health education, shared decision-making, supporting self-management, and personalised care planning (Ferrer 2015).

Similarly, there is good evidence that coordination, described as a strategy, or rather a range of strategies that can help to achieve integrated care (Leutz 1999; Van Houdt et al. 2013), can positively impact selected outcomes. For example, a systematic review by Powell-Davies et al. (2006) examined the effects of different strategies of coordination within primary care and other sectors (Table 3.1). The review assessed outcomes in terms of the percentage of studies that reported significant positive results. It showed that, generally, strategies that helped build relationships between service providers, through co-location, case management, or the use of multidisciplinary teams tended to be the most successful in achieving positive health outcomes and service user satisfaction. Also, strategies that involved providing systems and structures to support coordination tended to be more effective in terms of health outcomes than those providing support for service providers. The review by Powell-Davies et al. (2006) highlighted the need to recognise the context within which approaches are being implemented, whether individually or as part of a broader strategy, as well as the populations that are being targeted, in order to assess their impact and likelihood of success. This will be of particular importance where individual strategies can themselves be considered complex interventions.

This context specificity can be illustrated by the example of case management. Powell-Davies et al. (2006) noted that this may be a promising coordination strategy for some populations and settings, particularly in mental health and aged care (Powell-Davies et al. 2006). A 2015 Cochrane review of the effectiveness of case management approaches to home support for people with dementia found, based on 13 randomised controlled trials, that it was beneficial for some outcomes at certain time points. There was evidence of a significantly reduced likelihood of being institutionalised among those with dementia in the short and medium term, reduced carer burden, and reduced overall health care costs (Reilly et al. 2015). Conversely, a systematic review and meta-analysis of the effectiveness of case

Table 3.1 Summary of the evidence on the effectiveness of interventions to improve coordination in health care

Strategy	Proportion (%) of studies with positive outcome for health	Proportion (%) of studies with positive outcome for service user satisfaction	Proportion (%) of studies with positive outcome for cost saving
<i>Coordination of clinical activities</i>			
Structured arrangements for coordinating service provision between providers, including joint consultations, shared assessments and priority access to another clinical service (<i>n</i> 1/4 37 studies)	19/31 (61.3%)	4/12 (33.3%)	3/15 (20%)
<i>Communication between service providers</i>			
Interventions designed to improve communication between service providers, such as case conferences (<i>n</i> 1/4 56 studies)	26/47 (55.3%)	12/22 (54.5%)	3/21 (14.3%)
<i>Support for service providers</i>			
Interventions include support or supervision for clinicians, training (joint or relating to collaboration), and reminder systems (<i>n</i> 1/4 33 studies)	16/28 (57.1%)	8/14 (57.1%)	1/12 (8.3%)
<i>Support to service users</i>			
Interventions include joint education, reminders and assistance in accessing care (<i>n</i> 1/4 19 studies)	6/17 (35.3%)	3/6 (50.0%)	1/7 (14.3%)
<i>Systems to support coordination</i>			
Interventions include shared care plans, decision support, proforma, service user held or shared records; shared information or communication systems; register of service users (<i>n</i> 1/4 47 studies)	23/38 (60.5%)	7/19 (36.8%)	2/13 (15.4%)
<i>Relationships between service providers</i>			
Structured relationships between service providers including co-location, case management, multidisciplinary teams or assigning service users to a particular primary care provider (<i>n</i> 1/4 33 studies)	19/29 (65.5%)	8/12 (66.7%)	2/12 (16.7%)
All studies (<i>n</i> 1/4 80)	36/65 (55.4%)	14/31 (45.2%)	5/28 (17.9%)

Source Adapted from Powell-Davies et al. (2006)

management of patients in primary care that are ‘at risk’ of hospitalisation failed to demonstrate significant differences in service utilisation, mortality, or total cost among those receiving the intervention compared to usual care (Stokes et al. 2015). There was, however, some evidence of a (small) benefit for self-reported health and patient satisfaction.

It is beyond the scope of this chapter to assess the evidence base for case management, or indeed other strategies, tools, and instruments supporting integration, which are reviewed in greater detail elsewhere in this book. However, the example of case management provides a useful illustration of how a given approach or strategy seeking to enhance coordination and support integration may not always provide the most suitable strategy to enhance outcomes. Practitioners need to carefully consider the appropriateness for the target population. The review of case management of ‘at-risk’ patients also demonstrated that its effectiveness may be increased when delivered by a multidisciplinary team, when a social worker was involved, and when delivered in a setting rated as low in initial ‘strength’ of primary care (Stokes et al. 2015). These observations concur with the aforementioned review by Powell-Davies et al. (2006), which showed that coordinated care strategies that used multiple strategies tended to be more successful in enhancing health outcomes than those using a single strategy only. Specifically, those that helped structure relationships between providers and between providers and patients through, for example, co-location or multidisciplinary teams, were more likely to be successful.

3.4 The Economic Impacts of Integrated Care

As noted in earlier sections of this chapter, the move to more integrated care systems is often driven by the need to contain costs and associated with expectations of improved efficiency of service delivery. Yet, reviews that have also assessed the impacts on cost that can be attributed to integrated care programmes tend to report weak effects only (Martinez-Gonzalez et al. 2014; Ouwens et al. 2005). The following summarises the findings of our 2014 review of reviews, which sought to systematically assess the economic impacts of approaches and strategies supporting integrated care (Nolte and Pitchforth 2014). That review considered 19 systematic reviews and meta-analyses of diverse strategies that targeted a diverse group of people or populations. Reviewed studies focused on adults with specific chronic conditions including pain (Brink-Huis et al. 2008), depression (Gilbody et al. 2006a; van Steenberg-Weijnenburg et al. 2010), stroke (Langhorne et al. 2005), asthma (Maciejewski et al. 2009), heart failure (Phillips et al. 2004), COPD (Steuten et al. 2009) or those with multimorbidity (Smith et al. 2012). Others considered strategies for older people in the community considered to be frail (Oeseburg et al. 2009), who had long-term medical or social care needs (Tappenden et al. 2012), or who were to be discharged from hospital (Chiu and Newcomer 2007). Three reviews focused on adults with dementia or memory loss (Pimouguet

et al. 2010), those with severe mental health problems (Smith and Newton 2007), or those who received mental health care services (Steffen et al. 2009), while the remainder addressed populations defined by patterns of health service utilisation (Althaus et al. 2011; Shepperd et al. 2008; Simoens et al. 2011).

Strategies frequently targeted the interface between hospitals and primary care or community services, most often in the context of discharge planning or care transition (Althaus et al. 2011; Chiu and Newcomer 2007; Langhorne et al. 2005; Phillips et al. 2004; Simoens et al. 2011; Steffen et al. 2009). Several studies examined initiatives that sought to coordinate primary care and community services, often, although not always, involving medical specialists (Brink-Huis et al. 2008; Gilbody et al. 2006a; Smith et al. 2012; van Steenberg-Weijenburg et al. 2010) or extending further into social care services (Pimouguet et al. 2010; Smith and Newton 2007; Tappenden et al. 2012; van Steenberg-Weijenburg et al. 2010). The latter type of interventions tended to target older people with multiple care needs, those with dementia or with mental health problems. About half of primary studies considered by reviews were set in the USA, followed by the United Kingdom, Australia, Canada, New Zealand, the Netherlands, Spain, Italy, and Sweden.

The most common economic outcome measures were utilisation and cost, but reporting of measures was inconsistent and the quality of the evidence was often low. The majority of economic outcomes focused on hospital utilisation such as (re) admission rates, length of stay or admission days, and emergency department visits. For example, among reviews that considered care coordinating activities at the hospital-primary care or community services interface the majority reported evidence of reduced hospital utilisation (Chiu and Newcomer 2007; Langhorne et al. 2005; Phillips et al. 2004; Simoens et al. 2011; Steffen et al. 2009).

Most studies reported cost in terms of health care cost savings, most frequently in relation to hospital costs. Avoided costs or cost savings were typically derived from reduced hospital and emergency room utilisation. There was some evidence of cost reduction in a number of reviews although findings were frequently based on a small number of original studies, or studies that only used a before-after design without control, or both (Althaus et al. 2011; Brink-Huis et al. 2008; Chiu and Newcomer 2007; Phillips et al. 2004; Shepperd et al. 2008; Simoens et al. 2011; Steffen et al. 2009). Philips et al. (2004) highlighted the impact of health system setting on costs, demonstrating that pooled cost differences of comprehensive discharge planning for those with heart failure ranged from \$359 compared to usual care in non-USA based trials to \$536 in USA trials. Tappenden et al. (2012) further noted, in a review of structured home-based, nurse-led health promotion, the importance of differentiating between initial and longer-term costs (Tappenden et al. 2012). They reported that a community-based nursing programme for patients with Parkinson's disease had initially increased costs but over two years costs were lower.

Reviews also assessed the cost-effectiveness of selected integrated care approaches but again the evidence base was weak, frequently relying on single trials of a given intervention. For example, one review of approaches targeting frequent hospital emergency department users found only one trial that reported the

intervention to be cost effective (Althaus et al. 2011). One other review of structured home-based, nurse-led health promotion for older people at risk of hospital or care home admission concluded, based on three economic studies, that there was a high likelihood of cost savings associated with the intervention (Tappenden et al. 2012). However, one of the three primary studies suggested that there was little or no evidence for gains in quality-adjusted life years over usual care. Overall the evidence was difficult to interpret.

3.5 How to Interpret the Evidence Supporting Integrated Care

There is a wide and diverse evidence base, which appears to support a range of strategies and methods towards achieving more integrated care. However, it remains difficult to arrive at overarching conclusions about what works best in what composition and in what context. This is in part because the available evidence captures a wide range of, at times, very varied strategies and care approaches, which are not necessarily equivalent or comparable in relation to the type of service model, or the health and social care system context within which they are embedded. This challenge is greater where more complex combinations of interventions and service delivery changes are being implemented.

We have argued elsewhere that the interpretation of evaluation findings such as those presented here needs to be placed in the broader context of programme implementation specifically and issues around evaluation more widely (Nolte et al. 2012). For example, where an evaluation finds improvements in health outcomes but not in economic impacts, this might be because the length of evaluation was not sufficient to demonstrate economic gain. Indeed, a recent review of integrated care found statistically significant effects for studies that lasted longer than 12 months only (Rocks et al. 2020). Likewise, an evaluation might find that a given care approach improved outcomes for a subgroup of participants only; this might indicate that the intervention was suboptimal or not sufficiently targeted at those who would benefit most. Also, intervention effects will differ by target population and, importantly, by setting, in particular where initiatives involve a complex interplay of different actors as is the case with integrated care approaches.

Against this background, it will be particularly important to understand the quality of the available evidence in order to make sense of the variation in findings. Concerning economic evaluations for example, several authors highlighted their low quality as a major impediment to arrive at a robust evidence base suitable to inform decision making. Studies frequently rely on before-after studies without appropriate control, reducing the ability to attribute observed cost reductions to the actual intervention (Althaus et al. 2011). Other challenges include small sample sizes (Chiu and Newcomer 2007), the type of costs and cost categories considered (de Bruin et al. 2011), and whether these are limited to the health care sector or also consider the wider societal impact of (successful) integrated care strategies

(Gilbody et al. 2006b), alongside lack of reporting on reliability of estimates. All of this highlights the need for higher quality studies.

At the same time, to support this process, there may be a need to revisit the way in which evidence in the field of integrated care is being generated to advance our understanding of ‘what works’. This requires a clear definition of what constitutes effectiveness (or ‘success’) and, perhaps more critically, of the hypothesised mechanism(s) of expected effect(s), which, in turn, requires good theoretical understanding of how the intervention causes change and of the links within the causal chain (Craig et al. 2008). Much of the available evidence on outcomes rests on explicitly quantitative methods. However, as Cretin et al. (2004) have suggested in the context of chronic care, the complexity and variability of related interventions and programmes call for the use of mixed-method research. While there is an increasing body of work in this field, there remains relatively little research on methodological, analytical, or conceptual aspects of the use of qualitative approaches in the evaluation of complex care programmes. Recently, there has been a move towards emphasising ‘realistic evaluation’ (Pawson and Tilley 1997), which uses pluralistic quasi-experimental methods for evaluating complex interventions that are highly influenced by contextual factors. Realistic evaluation involves understanding what works for whom under what circumstances and places equal emphasis on external validity, generalisability, and cumulative learning.

3.6 Conclusions

This chapter has provided an overview of available evidence supporting integrated care. It highlights that evidence of the impacts of integrated care as a whole is difficult to derive, given the complex and polymorphous nature of a concept that has been approached from different disciplinary and professional perspectives. Instead, it may be more instructive for decision-makers and practitioners to draw on evidence of impact of core elements and strategies that can help to achieve integrated care. One such element is care coordination which in itself can be seen to comprise a series of strategies, including case management, co-location, and the use of multidisciplinary teams, along with support strategies such as shared care plans and decision support, which have been shown to enhance processes and the quality of care as well as health outcomes although the evidence of impact on cost remains weak.

A fundamental question that remains is whether integrated care is to be considered as an intervention that, by implication, ought to be cost-effective and support financial sustainability, or whether it is to be interpreted, and evaluated, as a complex strategy to innovate and implement long-lasting change in the way services in the health and social care sectors are being delivered and that involve multiple changes at multiple levels. Evidence reviewed here and in other sections of this book strongly supports the latter. This means that initiatives and strategies underway will require continuous evaluation over extended periods of time that will

enable assessment of their impacts on both economic and health outcomes. Such an approach will require sustained investment in research and in the development and implementation of integrated care initiatives to ensure that evaluation will inform service development in particular (Goodwin et al. 2012).

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4.1 Introduction

Over the past few years, the attention to the normative aspects of integrated care has grown (Hujala and Oksman 2018; Poulsen et al. 2019). Both in academic debate and in its application in practice, integrated care is now seen as more than ‘just’ a technical intervention for organizing and governing care services. For example, in their frequently used typology of healthcare integration, Fulop and colleagues (2005) present normative integration (addressing the role of values in the coordination of work and collaboration) as one of the two key dimensions of care integration. Similarly, Valentijn and colleagues’ Rainbow Model of Integrated Care (RMIC) distinguishes normative integration from functional integration, with the former referring to ‘the development and maintenance of a common frame of reference (i.e., shared mission, vision, values and culture) between organizations, professional groups and individuals’ (Valentijn 2015, p. 30). While the importance of effective collaboration and commitment has been widely acknowledged (Minkman 2012), practice experience demonstrates that more is needed to take integrated care forward. In addition to making arrangements, normative aspects such as the human factor and the underlying basis of commitment becomes

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increasingly important. By emphasizing this normative dimension, such frameworks provide a broader perspective on integrated care—stressing that it entails more than the ‘systematic integration’ of rules and policies (Fulop et al. 2005) or the ‘functional integration’ of funding, information and management mechanisms and practices (Valentijn 2015).

Other integrated care research also increasingly recognizes the role of values in services organization and governance. In integrated care research, values have been connected to organizational culture and performance of teams (Tietschert et al. 2019) and the decisions made by professionals (Miller et al. 2017). Values are increasingly seen as an important factor in explaining strong staff commitment (Goodwin 2013), informal coordination mechanisms (Valentijn 2015), teambuilding processes (Lette et al. 2019) and effective collaborative governance (Minkman 2012). On the other hand, values may also explain constraints to care integration, e.g., when collaborating partners pursue conflicting values, which may affect motivation and trust negatively (Kaehne 2018), or when stakeholders interpret values differently, which may complicate collaboration (Miller et al. 2017). The recent report of the International Foundation for Integrated Care ‘Realising the true value of integrated care: beyond covid-19’ defines nine building blocks for integrated services, of which the first one is shared values and vision (Lewis and Ehrenberg 2020).

The insights above have in common that values are seen as helpful in the explanation of less tangible mechanisms that play a role under the surface, such as commitment, trust and informal processes. These underlying mechanisms and processes may help explain why integrated care initiatives sometimes work and sometimes do not work. In this way, understanding the role and influence of values in integrated care initiatives can support their further improvement and development.

But although we know that values can play an important role in the explanation of less tangible mechanisms in integrated care, insight into which values play a role and how they can work is still missing. In order to further improve and develop integrated care initiatives, a shared frame of reference to discuss values is necessary. This chapter provides this frame of reference, by presenting a systematically developed list of values underpinning integrated care. First, we will explain values as a broader theoretical concept. We will then elaborate on which values are specifically relevant in integrated care and its different levels. Subsequently, we will conclude with a discussion on the practice implications of values in integrated care.

4.2 What Are Values?

Despite their presence in our everyday lives, values are intangible and they are defined in various ways. Following the sociological theorists that have been working on values in the past decades, values can be defined as conceptions of the desirable (Kluckhohn 1951), moral compasses (Spates 1983) or beliefs that a particular end-state is preferable to the opposite (Hitlin and Piliavin 2004).

Sociologists also stress that values can determine our identity (Hitlin 2003) and actions (Ajzen and Fishbein 1980). In short, five characteristics of values can be distinguished. Values (a) are concepts or beliefs, (b) refer to desirable goals, (c) transcend specific situations, (d) are guiding principles for action, and e) are ordered by relative importance (Schwartz and Bilsky 1987). As Miller et al. (2017) also state, values can be summarized in layman terms as ‘what people see as important and want to pursue’.

Since values refer to what is considered as important, the personal values of people can differ. In fact, people often vary in the relative importance they attach to certain values. In values theory this is also called a value hierarchy (Schwartz 2012). People often link values to particular aspects of their identity and/or group membership. Consider, for instance, the common values of colleagues, relatives or people from the same country of origin. This brings us to the question how the value hierarchies of people and groups are constructed. A variety of determinants influences people’s value orientations. On the one hand, personal factors play a role. Factors such as gender, age and family background can have a major effect on the value hierarchy of a person (Fung et al. 2016; Kalleberg and Marsden 2019). On the other hand, the values of people develop throughout their lives. Experiences related to education, interaction with people and cultural development can influence the value priorities of people. Translating this to the work context, many people take their personal values to work (Altun 2002). At the same time, employees often internalize organizational and professional values through socialization processes (Suar and Khuntia 2010).

Although values are intangible constructs, they are also often explicitly used. Organizations and institutions such as service providers and governments, for example, use values to create an image of their identity. Vision and mission statements or professional codes often consist of lots of values. In Boxes 1 and 2, two examples of these statements are shown. Values like trust, responsibility and transparency pass by. In this way, values are used to create a particular image of ‘who we are’ and ‘how we do things’ as an organization, regardless of whether this image is actually shared by employees.

In sum, values are abstract concepts that describe what people find important and want to achieve. The values of different people often vary and are linked to their identity and/or group membership. Personal factors such as family background determine the values of a person, but values also keep developing throughout their lives. In practice, we also often see organizations using values to frame their identities.

Box 1. Vision Statement Home Care Provider Buurtzorg in The Netherlands

“In our vision trust and responsibility should be leading instead of supervision and control. Nurses can do their job much better, if we do not control but trust. Our professionals are responsible for their own planning and activities. Our core values are: reliability, simplicity, thinking in solutions, practically and collegiality. In the care we provide, we strive for the best solution for clients, sustainable and effective. Because we work with self-organizing teams, we can tailor our services to the specific needs of our clients.”

Box 2. Mission Statement Local Integrated Multidisciplinary Teams

“Empowerment. We believe in empowerment and self-management. Our professionals look at what a person is still able to do, and what the social contacts of the person could do.

Proximity. Our professional work on neighborhood level, visit places where service users are located, are visible and can easily be found.

Transparency and clarity. Our service users should always know why, from whom and when she or he receives services.

Efficient. Our professionals are aware what services cost. They will do what is necessary, but take the costs of a solution into account.”

Knowing that people often differ in their prioritization of values, how does this then explain their actions and behaviors? In daily life, many issues are implicitly underpinned by values. Decisions, both important and trivial, are often a trade-off between competing values. In such a trade-off, values are being ordered by their relative importance. In dementia care for example, professionals have to often make trade-offs between the safety and freedom of their clients. A decision on whether or not to open the doors in a dementia care home has implications for both the freedom and the safety of the residents. In several situations, professionals need to balance between these two values; ensuring the residents' safety at all cost or the protection of their freedom (Driessen et al. 2017). These trade-offs may influence choices, decisions, actions and behavior in many situations.

The role of values is specifically relevant in integrated care because many different stakeholders are involved. First, service users, informal caregivers, professionals, policymakers and managers all have different roles, values and interests. Second, as integrated care transcends traditional sectors and domains, people from diverse backgrounds, cultures and traditions are cooperating and/or coordinating their work. They will therefore often have different value orientations. Third, integrated care programs and networks often consist of both public and private parties with different tasks and responsibilities such as funding, policy, implementation or service delivery. This also can lead to a difference in values. Consider, for example, the roles and responsibilities of governments, health insurers and health services providers. Whereas governments may highly value population health and the sustainability of the health system as a whole, health providers may attach more importance to the experience of their clients and the efficient delivery of services. In the following chapter, we will elaborate on what values are specifically relevant in integrated care.

4.3 Values Underpinning Integrated Care

Although people often differ in their value orientations, the concept of integrated care is often driven by a common philosophy. This philosophy is underpinned by a number of frequently appearing core values. In recent years, much important work has been done on the explication of integrated care values by fellow researchers. First, a set of core guiding principles has been proposed by the International Foundation of Integrated Care (IFIC) (Ferrer and Goodwin 2014). These principles of integrated care were developed by reflecting on the perspectives and views of stakeholders from different countries. In their ‘Global strategy on people-centred and integrated health services’ report, the World Health Organization (WHO) pleads for a unifying values framework (WHO 2015) and presents this set of guiding principles as items for this framework. This list, which was based on expert opinion and a large amount of practice experience, formed the basis for further development of integrated care values.

In order to study the values underpinning integrated care more systematically, a systematic review of literature has been conducted. This study identified the most frequently appearing values in integrated care literature (Zonneveld et al. 2018). Subsequently, this list of values was assessed and refined by a panel of 33 integrated care experts from 13 countries, following Delphi consensus methodology. This resulted in a refined list of eighteen values of integrated care. This list is shown in Box 3. The list of values underpins integrated care as a concept, across different countries and health systems.

Box 3. Values Underpinning Integrated Care (Zonneveld et al. 2020)	
Collaborative	<i>Establishing and maintaining good (working) relationships between users, informal carers, professionals and organizations —by working together across sectors, and in networks, teams and communities</i>
Comprehensive	<i>Users and informal carers are provided with a full range of care services and resources designed to meet their evolving needs and preferences</i>
Continuous	<i>Services that are consistent, coherent and connected, that address user’s needs across their life course</i>
Co-ordinated	<i>Connection and alignment between users, informal carers, professionals and organizations in the care chain, in order to reach a common focus matching the needs of the unique person</i>
Co-produced	<i>Engaging users, informal carers and communities in the design, implementation and improvement of services, through partnerships, in collaboration with professionals and providers</i>
Effective	<i>Ensuring that care is designed in such a way that outcomes serve health outcomes, costs, user experience and professional experience</i>
(continued)	

(continued)	
Efficient	<i>Using resources as wisely as possible and avoiding duplication</i>
Empowering	<i>Supporting people's ability and responsibility to build on their strengths, make their own decisions and manage their own health, depending on their needs and capacities</i>
Flexible	<i>Care that is able to change quickly and effectively, to respond to the unique, evolving needs of users and informal carers, both in professional teams and organizations</i>
Holistic	<i>Putting users and informal carers in the centre of a service that is 'whole person' focused in terms of their physical, social, socio-economical, biomedical, psychological, spiritual and emotional needs</i>
Led by whole-systems thinking	<i>Taking interrelatedness and interconnectedness into account, realizing changes in one part of the system can affect other parts</i>
Person-centered	<i>Valuing people through establishing and maintaining personal contact and relationships, to ensure that services and communication are based on the unique situations of users and informal carers</i>
Preventative	<i>There is an emphasis on promoting health and wellbeing and avoiding crises with timely detection and action by and with users, informal carers and communities</i>
Reciprocal	<i>Care is based on interdependent relationships between users, informal carers, professionals and providers, and facilitates cooperative, mutual exchange of knowledge, information and other resources</i>
Respectful	<i>Treating people with respect and dignity, being aware of their experiences, feelings, perceptions, culture and social circumstances</i>
Shared responsibility and accountability	<i>The acknowledgment that multiple actors are responsible and accountable for the quality and outcomes of care, based on collective ownership of actions, goals and objectives, between users, informal carers, professionals and providers</i>
Transparently shared	<i>Transparently sharing of information, decisions, consequences and results, between users, informal carers, professionals, providers, commissioners, funders, policy-makers and the public</i>
Trustful	<i>Enabling mutual trusting between users, informal carers, communities, professionals and organizations, in and across teams</i>

In addition to the list of 18 values and descriptions, the results of the Delphi study also reveal differences in value priorities on different levels of integration based on the Rainbow Model of Integrated Care (Valentijn 2015). Four levels of integration are distinguished. The personal level (in the RMIC: clinical integration) refers to the process of person-centered care delivery for a person with complex needs. The professional level (in the RMIC: professional integration) comprises interprofessional teamwork to deliver integrated services. The management level (in the RMIC: organizational integration) refers to issues within and between collaborating organizations. The system level (in the RMIC: system integration) refers to

the role of policies and systems in integrated care. We do not see these levels as separate worlds, but believe they should be interacting.

Figures 4.1, 4.2, 4.3 and 4.4 display the differences in relevance for each value. On the personal level, values referring to relationships and interactions with service users and informal caregivers are found to be relevant, such as trustful, reciprocal, preventative, respectful, person-centered, holistic and collaborative. On the professional level, the most relevant values are mainly connected to cooperative and multidisciplinary aspects of integrated care, such as reciprocal, co-ordinated, flexible, collaborative and trustful. When looking at the management level, the values efficient, effective and shared responsibility and accountability are seen as most relevant. These values refer to the governance side of the delivery of integrated care. Lastly, on the systemic macro-level, the most relevant values relate to implications for health systems such as led by whole systems thinking, comprehensive, effective and efficient. Summarized, ‘softer’ relational values are considered as relevant on the personal and professional level of integrated care, while more ‘hard’ rational values are seen as important on the management and system level where also has to be dealt with contextual factors like restrains in resources and budgets (Zonneveld et al. 2020).

In conclusion, research on integrated care values illustrates that despite the differences in context, health systems and interventions across countries, a set of common integrated care core values can be defined. At the same time, the study also shows that certain values may be more or less relevant on particular integrated care levels. On the one hand, this may explain why these integrated care levels are often not well connected. Service users, professionals, managers and policy and decision-makers, all acting at different integrated care levels, may find different

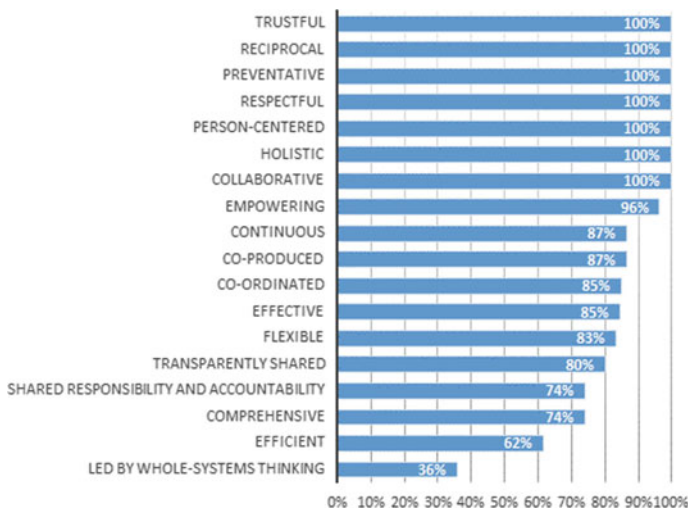


Fig. 4.1 Relevant values on personal level

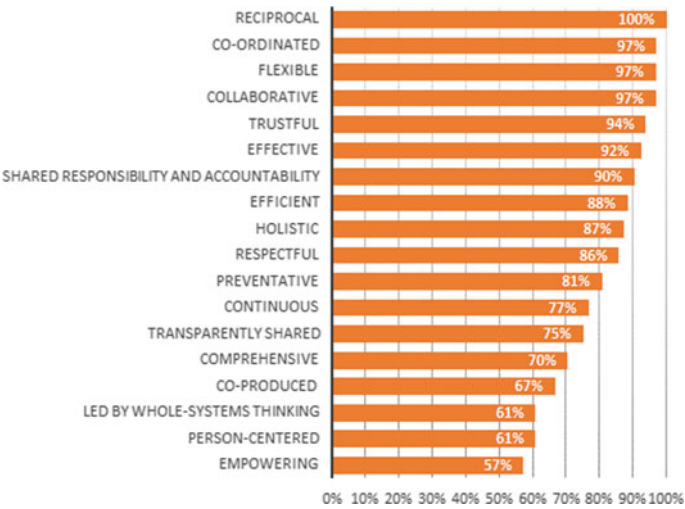


Fig. 4.2 Relevant values on professional level

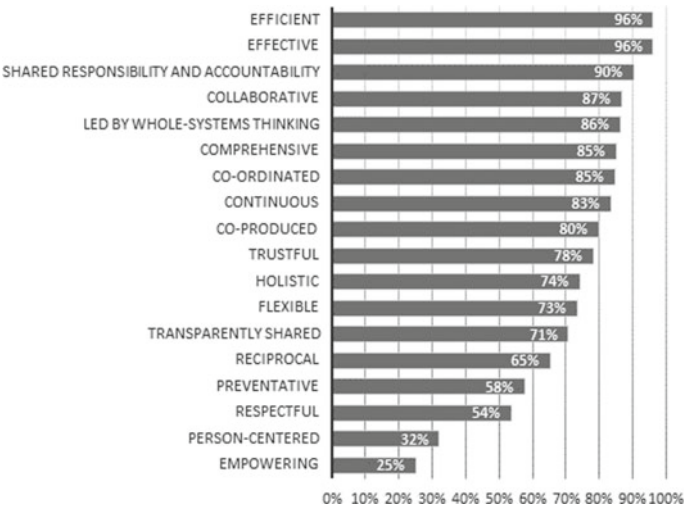


Fig. 4.3 Relevant values on management level

values important and base their behavior on these values. They may not understand or support the actions and behaviors of ‘the other.’ This may complicate the connectivity between levels and people. On the other hand, these insights offer us the opportunity to improve this connectivity. The awareness that different stakeholders on different integrated care have different roles and values can form the basis for a first step toward a better mutual understanding. A better understanding of one

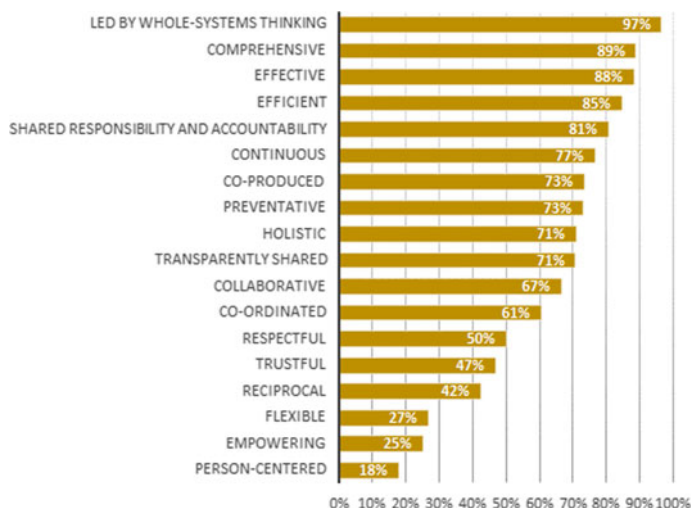


Fig. 4.4 Relevant values on system level

another's behavior, actions and motives, in order to better align and coordinate these—from service users to professionals, from governments to health insurers. The following chapter will elaborate on how this can be done in integrated care practice (Fig. 4.5).

4.4 Practice Implications

In the previous section, we presented a list of frequently appearing values underpinning integrated care. Values theory, however, also teaches us that the value orientations of people often differ, which may explain their actions and behaviors. In this section, we will elaborate on the implications of such diverse orientations for integrated care practice.

Integrated care is a collective undertaking in which people and organizations with different roles, backgrounds and interests work together. In pursuing such a collective undertaking, it is important to take account of stakeholders' potentially different value orientations. The roots of these differences may be found on various levels. First, people take their personal values to work. Such personal values may be shaped by, e.g., age, social background or past experiences. Second, people's various professional backgrounds also shape what they find important, being socialized in different professional fields and having internalized particular value orientations throughout their education. Third, people's position and role within their organization may also affect their value orientation, e.g., as a board of directors may have a somewhat different outlook on 'what matters' than a front-line professional worker. Fourth, and

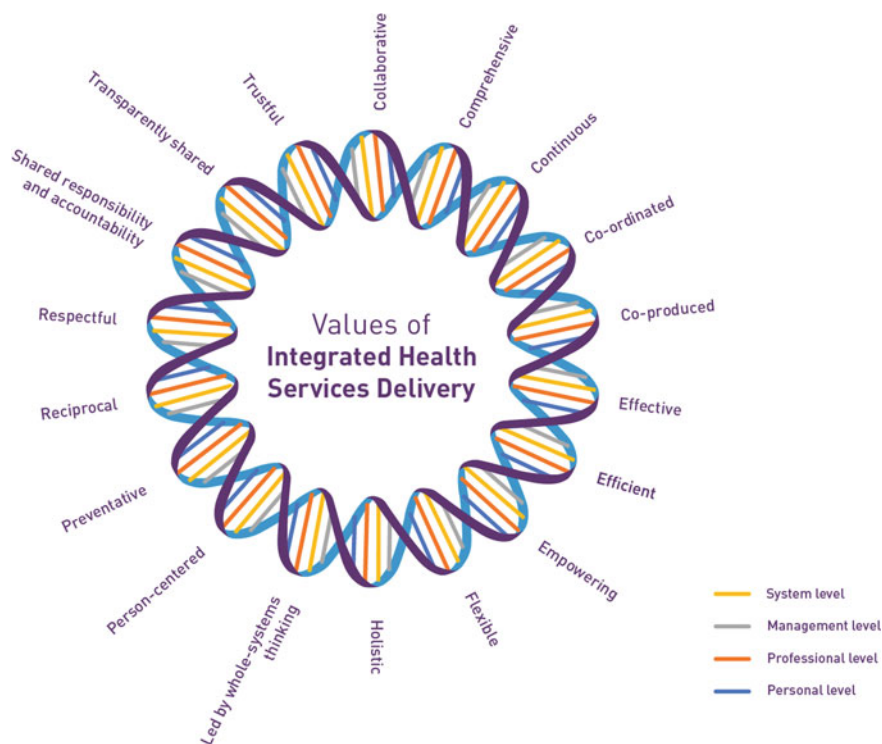


Fig. 4.5 Values underpinning integrated care

last, an organization may itself espouse particular values that can be reflected by its mission statement or within its organizational culture. These organizational values may not always be the same as people's personal value orientations, and they may also be different from the core values of other organizations. For example, even when both parties are pursuing integrated care, health insurance companies and patient advocacy organizations may prioritize and weigh particular values differently. In sum, within integrated care initiatives, various value orientations on the personal, professional and organizational level come together. These may not always be entirely congruent, which might complicate collaboration and coordination. This challenge needs to be addressed when pursuing the shared, overarching objective of delivering person-centered care across the care continuum.

Nevertheless, we should not forget that the diversity of perspectives also forms a key asset of integrated care. As integrated care programs and networks consist of people and organizations with various backgrounds, different value orientations will presumably always exist. This is not necessarily a bad thing—in many cases, such differences may complement each other. In integrated care, each partner brings its own values, expertise and knowledge to the table. Often, the whole is greater than

the sum of its parts. It is important to note here that collaborating partners do not have to change their own values or hide their personal, professional or organizational backgrounds.

At the same time, to collectively take the next step toward sustainable integrated care, it is important that stakeholders do establish a shared set of values as a basis for their joined-up efforts. While value differences will persist on a personal or organizational level, it is important for all parties involved to identify themselves with a shared set of integrated care values that they can translate to their everyday work practices. In other words, a shared set of values can provide the common ground on which stakeholders can build their collective efforts. Identification and explication of values may therefore be an important step to take in any integrated care initiative, program and network. Exploring shared values, acknowledging differences and being able to step into each other's shoes can be a first step in the development of a joint normative basis.

Box 4. Practice Example

A new regional integrated health care service was developed in the Eastern part of the Netherlands. In their first meeting, representatives of a hospital, two home care providers and multiple GPs discussed how to organize their joint service delivery. The collaborating partners swiftly agreed on tasks, roles and a project structure. A steering group was composed, key performance indicators were determined and a future development agenda was developed. However, after a couple of weeks, the first issues arose. It became clear that the professionals of the different partner organizations had different opinions and thoughts on how to work together or interact with service users. For example, some professionals were used to working autonomously and did not automatically share information, while others were used to a collaborative and transparent culture. And while some professionals were used to lots of intensive contact with service users and their informal caregivers, others were used to a more distant attitude towards their clients. At this moment, an important reflection was made: "We have to talk. I do not think we have ever really talked about our values and what is important to us. We never discussed our joint vision, its underlying values and how we want to achieve our objectives."

The list of integrated care values that we presented and discussed in this chapter can be used for such an assessment of stakeholder value orientations. The list offers a vocabulary for making these values explicit. It can, for example, be used as a value mapping tool to make personal, organizational and possible shared values more tangible. In a working session, integrated care stakeholders can 'map' values by prioritizing the eighteen values on a prioritization map. Thereafter, stakeholders share their value maps and orientations within the group of participants of the initiative. In order to take integrated care to the next level, it is important to engage

in a fundamental discussion within integrated care initiatives. In this discussion, preferably moderated by an experienced facilitator, similarities and differences in orientations can be identified, interpretations of values can be uncovered, and the most relevant personal, organizational and shared values can be unraveled. Core questions could be: What values matter most to the people and organizations involved? What do these values mean to them and how do they translate them to their own work setting? How can these abstract values form a concrete basis? What values should be leading within the collective initiative? And how does this relate to the individual people and organizations' priorities? What values are currently insufficiently addressed? These core questions can unravel both similarities and differences between people, between organizations and within the initiative as a whole. These similarities and differences in value orientations need to be addressed for the further alignment and development of integrated care initiatives. Defining a basic set of shared values can form a common starting point for integrated care leadership, policies and strategies.

4.5 Normative and Functional Aspects

The list of values presented in this chapter can contribute to the identification of values in integrated care initiatives, and subsequently to a discussion about normative aspects among stakeholders. When looking again at the earlier mentioned healthcare integration typology of Fulop and colleagues (2005) and the RMIC of Valentijn and colleagues (2015), normative integration and functional integration are positioned as the two essential mechanisms that ensure consistency between the micro (clinical)-, meso (professional, organizational)- and macro-levels (system) of integrated care. For the further development of integrated care, it is relevant to reflect on how these two mechanisms interact. Because in practice these mechanisms are intertwined and subsequently cannot be separated, we believe that we should not see them as separate worlds but as mutually influencing mechanisms. Consider, for example, the influence of functional aspects on normative integration. When professionals with different backgrounds are functionally located under one roof, their social interaction will increase. This may drive normative aspects of integration such as the development of a shared culture with common values. The other way around, normative aspects can also influence functional integration. A group of collaborating partners that, for instance, attach a high priority to values as 'collaborative' and 'trust' may be more likely to base their rules and decision making processes on horizontal relationships and mutual trust than on control and hierarchy. The relationship between normative integration and functional integration emphasizes the relevance of the presented list of values for the development of integrated care. Functional activities, rules and agreements should be normatively underpinned by values. For example, the requirements of an IT system for a multidisciplinary team need to be determined by the values of its users. When the end users see 'co-produced' and 'transparently shared' as leading values, they might use a file sharing tool more often.

In sum, the value orientations and interpretations of stakeholders in integrated care often differ. However, because values are rarely explicated, this is not always visible or tangible. The presented list can be used as a vocabulary tool to identify and explicate values, after which differences and similarities can be discussed and/or acknowledged. Thereafter, the values list can be used to underpin many functional activities in integrated care such as policies, decision making and implementation processes.

4.6 Conclusion

In this chapter, we have focused on the values in integrated care. As values often play a role in underlying integrated care processes and mechanisms, they may help us explain why integrated care initiatives work or do not work. However, values are not always tangible or visible and their role is often implicit. This chapter therefore presents a list of eighteen frequently appearing values underpinning integrated care, including insight into their relevance on the levels of integration. The list forms an international normative basis for the integrated care concept. Furthermore, it can be used for the identification and explication of values in integrated care practice, while also enabling discussion among stakeholders that appear to prioritize or interpret values differently.

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A. Mühlbacher and Susanne Bethge

5.1 Patients' Priorities for Integrated Healthcare Delivery Systems

Integrated care (IC) suits patient needs better than fragmented health services. It is needed to organize care around the patient (Davis et al. 2005) and is seen as a critical factor in a high-performance healthcare system (McAllister et al. 2007). Care coordination is a process that addresses the health needs and wants of patients, including a range of medical and social support services (Rosenbach and Young 2000; Tarzian and Silverman 2002). Still there are problems in defining care coordination (Wise et al. 2007) which may be caused by the lack of knowledge about patient priorities. Hence, patients must play a major role in designing the infrastructure and policies that will support the care coordination and integrated care approaches (Laine and Davidoff 1996).

If current trends continue, healthcare spending will leave governments bankrupt within decades (Henke et al. 2002). The problem is not lack of knowledge, nor is it the peoples' unwillingness to spend money. Rather, the difficulties lie in the understanding of peoples' priorities and preferences. Porter and Teisberg state "health care is on a collision course with patient needs and economic reality"

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(Porter and Teisberg 2006). This is one of the biggest problems policymakers are facing in the coming years, and it raises questions of how services should be provided. The Institute of Medicine Report “Crossing the Quality Chasm” (2001) emphasizes that health decisions should be customized based on patients’ needs and values. Most, if not all, newly developed programmes so far are conceptualized in a “top-down” manner by the government and healthcare administration with little involvement of the general public (Wismar and Busse 2002). “Healthcare systems are challenged to effectively meet the wants and needs of patients by tailoring interventions based on each person’s (...) preferences as well as personal and social context” (Sevin et al. 2009). In health policy terms, this refers to services “closely congruent with, and responsive to patients’ wants, needs and preferences” (Laine and Davidoff 1996). The most powerful structural innovation will be based on a paradigm shift—patient-centred care. Patient-centred care takes numerous forms and should be based on patient evidence as provided by preference data.

Patient Preferences The term “patient preferences” still lacks a consistent definition; despite this, there appears to be convergence in the view that patient preferences are statements made by individuals regarding their needs, values and expectations and the relative importance of treatment properties. Therefore, these preferences refer to the individual evaluation of dimensions of health outcomes, treatment characteristics or health system attributes. Based on the existing literature, integrated care can be differentiated into attributes, such as:

- (1) **Organization of care:** The organization of care can be seen as a function that helps to ensure that patients’ preferences for health services and information are met (National Quality Forum 2006). It is widely acknowledged that care coordination across all healthcare settings and related disciplines will improve the quality of health care and therefore satisfy the preferences of the patients involved (Adams and Corrigan 2003). Physicians in larger medical groups, particularly those who are part of integrated care programmes, perform more favourably on all patient experience measures than those in smaller, less-integrated practice settings (Rodriguez et al. 2009). Some findings have shown that individuals within an integrated care system had shorter average hospital stays and lower costs than comparison groups (Criscione et al. 1995; Liptak et al. 1998). When addressing different social, developmental, educational and financial needs, the design of services has to take heterogeneity of patients and families into account. One of the biggest challenges in care coordination and integrated care is identification of the necessary set of attributes that are needed to obtain optimal results. Clinicians need to understand and tailor care to the wider whole-person context—including whatever non-medical factors may affect the success of medical care (Peek 2009).
- (2) **Interpersonal care:** In integrated care, physician–patient communication is the fundamental platform for health service delivery. An important component is the creation of individualized care plans “that establish a partnership among practitioners, patients and their families (when appropriate), to ensure that decisions respect patients’ needs and preferences” (Institute of Medicine 2001).

Patients placed the highest value on seeing a physician who knew them well, followed by seeing a physician who was interested in their ideas, one who asked about social and emotional issues and one who involved them in decisions (Cheraghi-Sohi et al. 2008). Preference studies using discrete choice experiments have shown that communication is highly valued (Vick and Scott 1998; Scott and Vick 1999; Morgan et al. 2000; Chapple et al. 2002; Scott et al. 2003; Gerard and Lattimer 2005; Rao et al. 2006; Al Mulley et al. 2012). Although patients with chronic diseases valued shared decision-making, it was of lower relevance than whether the physician seemed to listen (Longo et al. 2006). Longo et al. question the high-priority patients place on communication issues and suggest critical examination (Longo et al. 2006).

- (3) Technical care: Technical care—the quality of clinical care—is another key dimension (Campbell et al. 2000). A discrete choice experiment reported that technical care was the most important factor in determining patient choice of a physician (accounting for 27% of the variance), compared with waiting time (15%), billing problems (20%), time to get a referral (18%) and who made healthcare decisions (20%) (Markham et al. 1999). Cheraghi-Sohi et al. (2008) argue that attributes used to test the priorities placed on patient-centred care in published studies have not accurately reflected the complexity of the patient-centred care concept. Little is known about patients' assessment of technical care and how these assessments correlate with other objective measures (Rao et al. 2006). A study conducted in the USA asked patients to choose between physician report cards with different scores for interpersonal and technical care. Findings showed that more patients preferred the physician with high technical care scores (Fung et al. 2005). The three described meta-dimensions of IC can further be explained by seven sub-domains. In qualitative and quantitative research, these seven preference dimensions with three attributes each could be evaluated and identified as patient relevant in respect of IC (Juhnke and Mühlbacher 2013).
1. Access described by waiting time for an appointment, travel time care provider, out of pocket costs
 2. Service and facilities described by guidance within the facility, medical devices and furnishings, friendliness and helpfulness of staff
 3. Data and information described by patient's health record, information about performance, accurate health information
 4. Professional care described by treatment guidelines, experience of care provider, patient education
 5. Coordination and continuity described by multidisciplinary care, care transition, clinical information exchange
 6. Individualized healthcare described by proactive care, case management, attention to personal situation
 7. Personal care described by trust and respect, attentiveness of care providers, shared decision-making.

The Question What do patients want from integrated care? Much work remains to be done for care coordination to become a standard feature of health care.

Integrated care aims to achieve higher-quality care, lower costs and greater patient satisfaction. Individual preferences on integrated care must be considered for a range of attributes, such as technical and interpersonal care. Designing services that are sensitive to patients' preferences in the context of limited resources may require policy- and decision-makers to choose between attributes (Wensing et al. 1998; Campbell et al. 2000; Coulter 2005). Two of the core contributions needed to achieve this goal are: assessment of the value of integrated care for different patient populations and development of measures for integrated care quality (Antonelli et al. 2009). The published literature does not clearly specify the relative importance patients place on these attributes. In order to promote integrated care, policymakers need to understand patients' priorities and preferences.

In order to make integrated care more congruent with patients' needs, patients' preferences for different attributes need to be analysed (Laine and Davidoff 1996). Moreover, meeting expectations on a range of attributes may be difficult within the constraints of limited budgets; this has led to interest in methods for assessing priorities (Ryan et al. 2001a). "One promising method is the discrete choice experiment, used in psychology, marketing and economics" (Ryan et al. 2001a). McFadden (1973) introduced feasible techniques for estimating a complete characteristics-based model of demand.

5.2 Stated Preference Studies: Method and Study Design

Discrete Choice Experiment The value of goods and services depends on the nature and level of the underlying attributes (Lancaster 1966, 1971). Healthcare interventions, services or policies can be described by their attributes (Hauber 2009). A key feature of these methods is the specification of utilities associated with the alternatives in terms of choice characteristics and individual preferences (Ben-Akiva and Lerman 1985). Stated preference studies focus on investigating the trade-offs between crucial attributes (Ryan and Hughes 1997; Ryan and Farrar 2000; Ryan and Gerard 2003). Discrete choice experiments are the most important form of stated preference studies and determine whether consumers are willing to trade off some of the attributes against others (Ryan et al. 2001b). DCEs have recently gained importance in the study of innovative health technologies and non-market goods (Lancsar et al. 2007; Lancsar and Louviere 2008; Ryan et al. 2008) or where market choices are severely constrained by regulatory and institutional factors (Ryan and Farrar 2000). The US Food and Drug Administration (FDA) has already considered preference data within a regulatory decision for medical devices (US Food and Drug Administration (FDA) 2014), and the German Institute for Quality and Efficiency in Health Care (IQWiG) has conducted two pilot studies to preference methods (Danner et al. 2011; Mühlbacher et al. 2016).

The discrete choice technique is already used to elicit preferences in primary care (Vick and Scott 1998; Scott and Vick 1999; Morgan et al. 2000) and gaining more and more importance (de Bekker Grob et al. 2010; Clark et al. 2014). The application of DCEs has been extended to take account of providers preferences (Ubach et al. 2003) or insured preferences for health system attributes (Telser et al. 2008). Moreover, the technique has been used to evaluate patient-centred outcomes in the provision of care (Mühlbacher et al. 2008, 2009, 2014; Mühlbacher and Bethge 2014, 2015; Ostermann et al. 2015). For policy analysis, it might be interesting to calculate how choice probabilities vary with changes in attributes or attribute levels, or to calculate secondary estimates of money equivalence [willingness to pay (WTP) or willingness to accept (WTA)] (Kleinman et al. 2002), risk equivalence [maximum acceptable risk (MAR)] (Johnson et al. 2007) or time equivalence for various changes in attributes or attribute levels (Johnson et al. 2009). Findings on the reliability and validity of DCEs in healthcare settings are encouraging (Bryan et al. 2000; Bryan and Parry 2002). A DCE can be described in terms of detailed checklists (Bridges et al. 2011; Johnson et al. 2012, 2015; Mühlbacher et al. 2013).

To analyse patient and insured preferences in IC, two very similar studies have been conducted in USA (Mühlbacher et al. 2015a) and Germany (Mühlbacher et al. 2015b) and should help to illustrate preference measurement in IC. An identical stated preference method was used to assess patient preferences in different healthcare systems and cultural backgrounds. Furthermore, a study was realized that explored the impact of the contextual factor of the communicator of IC programmes and the resulting effects within choice behaviour (Bethge et al. 2015).

5.3 Preference for Integrated Healthcare Delivery Systems

Qualitative Methods Both studies in the USA and in Germany included an identical conceptual framework linking organizational structure to potential preferences. The framework was developed by systematic literature reviews as well as quantitative surveys and factor analysis about the very differentiated needs and expectations in respect of integrated care (Juhnke and Mühlbacher 2013). The final framework included the specification of different organizational levels of healthcare delivery and corresponding preference dimensions as described in the first part of this chapter and as can be seen in Fig. 5.1.

Quantitative data were obtained by means of two identical discrete choice experiments (DCEs) integrated in online surveys. Within the experiment, participants were presented two alternative scenarios of hypothetical healthcare delivery systems and asked to choose between them. Each scenario included six attributes with three specific levels.

Based on the assumption that patients' choices are influenced by latent concepts such as sociodemographic characteristics, experience, knowledge and attitudes, it was also important to elicit respondent-specific experiences, attitudes and

Level	Preference Dimension	Attributes		
Individual Level	Interpersonal Care	Shared Decision-Making	Attentiveness of Care Providers	Trust and Respect
	Individualised Healthcare	Attention to Personal Situation	Case Management	Proactive Care
Process Level	Coordination & Continuity	Multidisciplinary Care	Care Transition	Clinical information Exchange
	Professional Care	Experience of Care Provider	Treatment Guidelines	Patient Education
Organizational Level	Data & Information	Patient's health Record	Information about Performance	Accurate health Information
	Service & Facilities	Friendliness and Helpfulness of Staff	Medical Devices and Furnishings	Guidance within the Facility
	Access	Waiting Time for an Appointment	Travel Time to Care Provider	Out of Pocket Costs

Fig. 5.1 Framework: patient-centred healthcare delivery (Mühlbacher et al. 2015a)

sociodemographic information. These characteristics may influence preferences in a systematic way, and heterogeneity within subgroups can be analysed. Therefore, these additional data were included in the survey.

Sample Characteristics Within the two studies, n 3900 participants (only patients assigned in healthcare system) in the USA as well as n 1322 participants (insured sample) in Germany could be included within the final preference estimations. Table 5.1 presents some sociodemographic characteristics of both study samples.

US Preference Results The feature “out of pocket costs” was a very important attribute within the DCE in the US study. In DCE 1 regarding patient involvement, “trust and respect” (0.65600) was slightly higher than cost. “Attention to personal situation” (0.42178) was as well of great importance. In DCE 2 addressing preferences at the point of care, “shared decision-making” (0.71058) and “access to patient health record” (0.46432) were highly valuable to patients. In DCE 3 focusing on personnel in healthcare delivery systems, “multidisciplinary care” (0.74096) was ranked highest. Lastly, in DCE 4 analysing features of the organization of healthcare delivery systems, “treatment guidelines” (0.44834), “clinical information exchange” (0.38334) and “case management” (0.37689) were of almost equal value to patients. Differences in individual living conditions influenced respondents’ preferences.

Table 5.1 Respondent characteristics of US and German participants

Characteristic	US patient sample (N 1/4 3900) No. (%)	German insured sample (N 1/4 1322) No. (%)
<i>Sex</i>		
Men	1347 (34.5)	652 (49.3)
Women	2553 (65.5)	670 (50.7)
<i>Marital status</i>		
Married	2431 (62.3)	605 (45.8)
Single	568 (14.6)	278 (21.0)
Divorced or separated	432 (11.1)	143 (10.8)
In a committed relationship, but not married	311 (8.0)	277 (21.0)
Widowed	158 (4.1)	19 (1.4)
<i>Self-rated health</i>		
Excellent	408 (10.5)	34 (2.6)
Very good	1249 (32.0)	252 (19.1)
Good	1270 (32.6)	708 (53.6)
Fair	741 (19.0)	295 (22.3)
Poor	216 (5.5)	33 (2.5)
Not sure	16 (<0.1)	–

German Preference Results The additional costs (out of pocket costs) were again of highest relevance in patients' choice. Next to the "costs" attribute, in DCE 1 (patient involvement) "patient education" (coef.: 0.2196) was of great importance, and in DCE 2 (point of care) it was "waiting for an appointment" (coef.: 0.335). In DCE 3 (personnel), "experience of care provider" (coef.: 0.289) had strong influence on decisions. In the fourth DCE (organization), "medical devices and furnishings" (coef.: 0.464) were highly relevant. [Detailed results of the German study can be found at Mühlbacher et al. (2015a), and details for the US study are available at Mühlbacher et al. (2015b)].

Comparison of Results The inclusion of an identical cost attribute across all content blocks provides the means to compute a common metric across all 21 attributes. Figure 5.2 represents the comparison of the relative importance of the attributes for the US and the German study (not discussing the issue of scale heterogeneity). The estimates are sorted in relation to the US results beginning with the highest important attribute. It can be seen that the US participants were most influenced by shared decision-making, multidisciplinary care and trust and respect within their decision for an integrated care programme. These are attributes that relate to individual or process aspects of integrated care. On the contrary, the German participants valued medical devices and furnishings, waiting time for an appointment as well as the experience of care provider highest. This means the German population is more focused on organizational aspects of healthcare delivery and puts a high value on the state of medical equipment.

The differentiation of the first five ranks in comparison between both study groups can be seen in the following chart (Fig. 5.3).

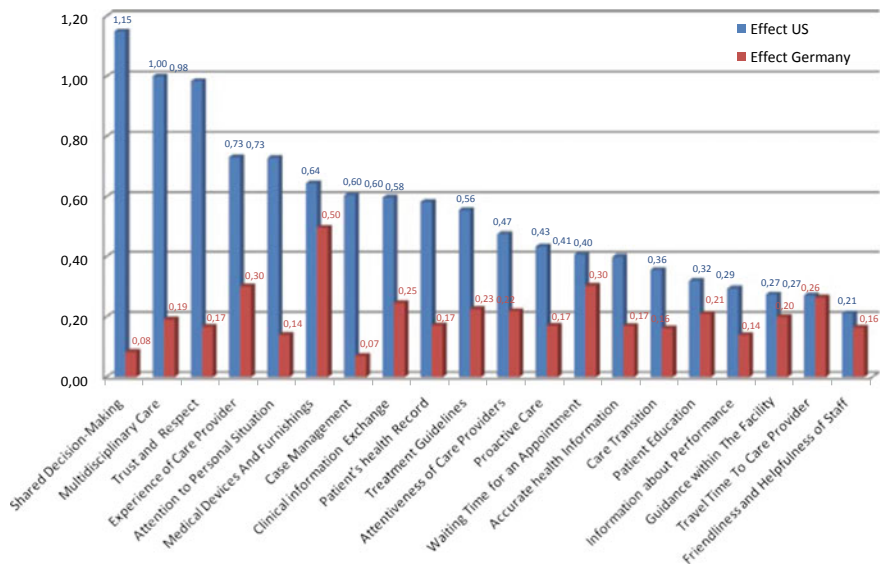


Fig. 5.2 Overall assessment of all attributes in relation to cost attribute

Level	Preference Dimension	Attributes		
Individual Level	Interpersonal Care	Shared Decision-Making 1	Attentiveness of Care Providers	Trust and Respect 3
	Individualized Healthcare	Attention to Personal Situation 5	Case Management	Proactive Care
Process Level	Coordination & Continuity	Multidisciplinary Care 2	Care Transition	Clinical information Exchange 5
	Professional Care	Experience of Care Provider 4 3	Treatment Guidelines	Patient Education
Organizational Level	Data & Information	Patient's Health Record	Information about Performance	Accurate health Information
	Service & Facilities	Friendliness and Helpfulness of Staff	Medical Devices and Furnishings 1	Guidance within the Facility
	Access	Waiting Time for an Appointment 2	Travel Time to Care Provider 4	Out of Pocket Costs

= Overall ranking US = Overall ranking Germany

Fig. 5.3 Rank order comparison USA and Germany, place 1–5

Conclusion The presented results display the complexity of preferences and their dependency on cultural and healthcare system differences. As stated by the WHO *“There is no perfect combination or a “one size fits all” solution”* for patient-centred and integrated health services. Nevertheless, the person with its needs and expectations is/and needs to be in the centre of integrated care (World Health Organization (WHO) 2015).

The novelty of the presented results is the combination of qualitative and quantitative methods for building a conceptual map of patient-centred outcomes that can be used to plan comprehensive assessment of patients' preferences in integrated care. The framework concludes important attributes and endpoints and allows sorting them in categories and subcategories. Further research is needed to distinguish the possible interpretations of the presented attitudes or preference dimensions and to take notice of heterogeneity within patient population. In addition, the development of a conceptual framework can be used as foundation of further stated preference measures.

It is necessary to evaluate what patient preferences are to help researchers, payers, regulators, physicians and patients to understand the relative importance of each treatment attribute and the willingness of patients to trade among treatment attributes. Designing integrated care around patients' preferences has the potential to improve the effectiveness of health care by improving adoption of and adherence to clinical treatments or public health programmes. An important area for future research is the question: What are the implications of patient-centred care? Understanding how patients and other stakeholders perceive and value different aspects of integrated care is vital to the optimal design and evaluation of programmes.

5.4 Discussion and Outlook

Patient-centred outcomes will provide objective information about the impact on patient involvement, the experiences of patients, and their needs and wants. The publication of patient preference data will help insurers, policymakers and others to promote patient-centred integrated care as the new standard of primary care. The data can be communicated through medical and economic journals, congresses and media.

Because of the lack of information on patient needs in the decision-makers' assessment of health services, the individuals' preferences often play a subordinate role at present. The patients' perspectives and desires in healthcare decisions are often not sufficiently considered. However, shared decision-making with the involvement of patients in treatment decisions has been encouraged in recent years.

Though not examined in this chapter that has focused on patient preferences, it should be noted that a key aspect in the development of interpersonal care is the ability to engage and empower patients as partners in their own care. There is good evidence to demonstrate the value of empowerment strategies with patients

suggesting that approaches such as health literacy, shared decision-making and self-management support should be better embedded in integrated care programmes than currently seems to be the case (Ferrer 2015). The recent publication of a Global Strategy on Integrated People-Centred Health Services by the World Health Organization presents evidence that enabling individuals to make informed choices and supporting them to understand their responsibilities as well as their rights can significantly enhance health outcomes. The WHO goes further to argue that an equal and reciprocal relationship between health professionals and patients is required to support more sustainable care systems (World Health Organization (WHO) 2015).

The findings of such studies supply important information on the benefits of integrated care from the patients' point of view. If patient needs are taken into account adequately, it is safe to assume that this will increase their satisfaction with integrated care programmes. Heterogeneity within preferences due to racial and ethnic disparities, age or illness can be documented and considered in the design of healthcare services. Integrated care schemes will not work unless it is accepted that different patient groups need different care programmes and that sensitivity to cultural factors and the local context of application are important to engage patients and support their needs and preferences effectively.

The presented studies reviewed in this chapter also support efforts for increased consideration of patient benefit as an essential quality criterion in the assessment of integrated care. Especially where it is difficult to clearly differentiate between services in terms of medical and financial aspects, comprehensive information on patient benefits (and to that of communities as well) can be very useful in prioritizing approaches to care and treatment. Studies of this type can thus help to stimulate fresh discussion and lead to the formulation of increasingly person-centred care concepts in the long term.

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Integrating Health- and Social Care Systems

6

John Eastwood and Robin Miller

6.1 Introduction

It has long been recognised that social issues have a strong bearing on people's health and well-being. Whilst medical treatments are essential to address underlying infections and physical malfunctioning, these are insufficient by themselves to maintain and promote the health of a population. Wider social contexts such as poverty, housing, hygiene, employment and education play a fundamental role in the incidence of disease. These must be considered and connected issues addressed to achieve better health for all. Vaccines can provide important immunity that will help to eradicate a disease, but it is only by societal coordination and development of associated social norms that vaccines are successfully introduced. Health interventions may be able to prolong the life of people with a long-term health condition, but social issues enable life to be of better quality—i.e. a life worth living and acute care can only successfully operate if people are supported post-crisis to return or access support in the community. In relation to mental health, social networks and access to employment are often the most influential in achieving better well-being.

Given that health and social care should be at the heart of all integrated care it could therefore be questioned as to why there is a need for a separate chapter on this topic within this compendium. And yet practitioners of integrated care are well aware that we are far from achieving integration of health and social care in either

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policy or practice. Integrated care is often still interpreted as being about integrating primary and secondary medical services, and attempts remain disconnected from the social system upon which people rely for the essentials of living. This narrow view of integrated care should be challenged and the principles of integrated care systems extended across sectors in partnership with communities and their citizens. Integration of health and social care has been difficult to achieve using structural and organisational approaches given the significantly different funding streams, regulatory frameworks and professional and organisational cultures. Given the demonstrated importance of the social determinants of health, it is only by putting the social needs of individuals, and their families, at the centre, can we achieve the integration we strive for.

In taking a person-centred approach to the provision of care and support, it is necessary to keep ‘all matters in scope’ including biological, psychological, physical and social environments and life-course. In this chapter, we will consider integration of health and social care in relation to the direct delivery of support to individuals and their families (i.e. clinical and service integration) and integration of health and social care in relation to addressing the social determinants of health (i.e. population and system integration). We will then focus on the importance of workforce and what practically can be done to enable health- and social care professionals to collaborate better. We will begin though by considering what is meant by social care.

6.2 What Do We Mean by Social Care?

Whilst the individual concepts of ‘social’ and ‘care’ are ones that transcend boundaries, the term ‘social care’ is not widely used or consistently understood internationally. In relation to the delivery of services, in the UK (which has been influential in relation to integrated care developments), social care refers to a range of direct support to people who are vulnerable and/or have lost independence due to age, disability, mental health or other issue. Classically, this involves support such as tending to personal care (i.e. washing, toileting and dressing), maintaining a household (i.e. cleaning and shopping), supervision (through staff and/or electronic devices) and support for informal carers (i.e. home- or residential-based respite). The support can be provided in the person’s own home or in designated facilities such as residential care or supported housing. In many other countries, such services are not separately denoted as ‘social care’, but rather included within the concept of ‘long-term care’. The OECD (2019) defines this as a ‘range of medical, personal care and assistance services that are provided with the primary goal of alleviating pain and reducing or managing the deterioration in health status for people with a degree of long-term dependency’ (OECD 2019, p. 1). Long-term care therefore includes community-based health services as well as the UK-defined social care. Other terms are also deployed—in Australia—for example, ‘aged care’ denotes long-term care for older people. Alongside long-term care, another commonly used terms are ‘social

services’ or ‘human services’—this incorporates the support outlined above but also wider services to promote someone’s well-being, such as those related to employment, education, leisure and financial support. These sectors also often have responsibilities in relation to safeguarding people who are vulnerable from exploitation and/or abuse.

However one denotes such provision (and we shall refer to them as ‘direct social care services’), an important context is that much of the non-health components of long-term care are provided by families and other informal networks, rather than by formal agencies. Furthermore, such care is largely provided by women. This can restrict women’s ability to access paid work and progress careers of choice. Informal care giving is also related to higher poverty rates and prevalence of mental health problems. Formal direct social care services are commonly provided by a mixed economy of public, private and charitable organisations and public funding routes include social insurance, taxation and/or user charges. Whatever the funding model, there are common concerns regarding the capacity of formal provision to cope with increasing demand, ensure the quality of care due to tensions between funding and pressures and manage the economic impacts of populations living longer and with multiple conditions (Spasova et al. 2018). In response to the latter, one common strategy being pursued by many countries is to reduce reliance on institutional care through strengthening home-based care.

Many countries experience challenges relating to the recruiting of a skilled workforce due to restricted pay, unsociable hours and low status of such roles. Such concerns are not limited to advanced market economies. For example, the (WHO 2017) has estimated that in Ghana, more than 50% of people between the ages of 65 and 75 years require some assistance with daily activities. For those 75 years and older, the percentage jumps to more than 65%. This compares with Switzerland in which the proportion is less than 5% and 20%, respectively.

Alongside direct services to individuals and their families are ‘activities that address health-related social risk factors and social needs’ (National Academies of Sciences 2019, p. 28). Social variation in health outcomes has been long studied and appreciated. A historical social epidemiological perspective is provided by Berkman and Kawachi (2000). The authors discuss several relevant concepts including a population perspective, the social context of behaviour, multilevel context, a developmental and life-course perspective and the possibility of a general susceptibility to disease linked to the cumulative effects of stress. Pearlin (1981) hypothesised that health disparities arose to a substantial degree from differences in life-time exposure to social stress (Turner 2010). Social determinants of health can be defined as the economic and social conditions that influence both individual and group differences in health and well-being. The 2011 World Conference on Social Determinants of Health affirmed that health inequities are unacceptable and noted that these ‘inequities arise from the societal conditions in which people are born, grow, live, work and age, including early childhood development, education, economic status, employment and decent work, housing environment and effective prevention and treatment of health problems’ (World Health Organization 2011).

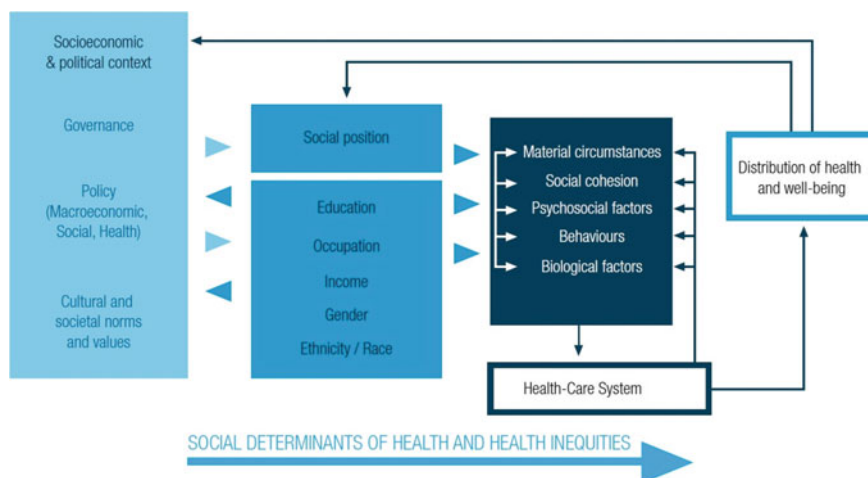


Fig. 6.1 Commission on social determinants of health conceptual framework (WHO 2011)

Whilst the determinants are primarily rooted in macro-resource allocation, the effects are experienced by individuals and families in their daily lives and across generations (Fig. 6.1).

Lantz and colleagues observe that “public health activities in the late nineteenth and early twentieth centuries focused on ‘upstream’ causes of poor health, including poor sanitation, overcrowded and squalid housing conditions, work-related hazards, food security and nutrition” with consequential sharp declines in mortality. Coming from a *population health* perspective the authors argue for continued attention to key social and economic causes and caution against the medicalisation of the social determinants of health (Lantz et al. 2007). The US Healthy People 2020 Plan (Health and Services 2001) identifies four key aspects of society to be addressed in regards to the social determinants alongside healthcare services: economic stability, education, social and community context, neighbourhood and built environment. Social care from this perspective refers to activities that seek to address these wider determinants of health. There is increasing recognition in such approaches that all communities, even those which face considerable disadvantage, will have their strengths based on local social and cultural networks. Building on these local assets, rather than solely problematising the people and their communities, provides a more constructive, enabling and sustainable solution to underlying and embedded challenges.

6.3 Integrating Health- and Social Care for Populations

6.3.1 Population Health Improvement Approach

Lantz and colleagues (2007) observe that healthcare and public health professionals may have different interpretations of the term population health, with healthcare

leaders using the term to describe cohorts of individuals served by health plans or clinical services. By contrast, for public health leaders, the population of interest is all people living in a geographical area, such as country or region. The differences between these two views may be more profound and influenced by quite different beliefs and values.

The modern population health approach has a pedigree that includes the Alma-Ata Declaration on Primary Health Care (WHO 1978) and the Ottawa Charter of Health Promotion (WHO 1986). The Alma-Ata Declaration of 1978 was a major milestone in the field of public health, and it identified primary health care as the key to the attainment of the goal of 'Health for All' around the globe. It was based on the principles of equity and community participation in health planning and policy making, through an inter-sectoral approach. The Ottawa Charter for Health Promotion incorporated five key actions of: (1) building healthy public policy; (2) creating supportive environments for health; (3) strengthening community action for health; (4) developing personal skills; and (5) re-orienting health services.

This population health 'improvement' approach to the social determinants of health (SDOH) seeks to address the underlying structural factors such as economic, education, housing and income security policy and the broader values, cultural and institutional contexts that shape the distribution of resources. The approach is intended to improve the health and well-being of the whole society and not just the poorest or most marginalised. When integrating health and social service systems, this approach is operationalised through a whole of society approach to 'health in all policies', universal health care, housing, education and full employment. At a local level, population-based initiatives may be represented by safe communities and healthy city initiatives. Through such approaches, all citizens benefit from reduced crime, strong social cohesion and clean air.

The relevance of the population health 'improvement' approach to integrated care may not be immediately apparent, but it can be advanced that integrated health and social care will benefit from strong community social cohesion, health literacy, coordinated services and shared governance. This is what the Ottawa Charter calls 'Supportive Environments for Health'. The recently ratified WHO framework on integrated people-centred services (WHO 2016) takes a similar population health approach and has echoes of both the Alma-Ata Declaration and Ottawa Charter. The framework has five interwoven strategies: (1) empowering and engaging people and communities; (2) strengthening governance and accountability; (3) re-orienting models of care; (4) coordinating services within and across sectors; and (5) creating enabling environments. As with the Alma-Ata Declaration, the WHO framework on integrated people-centred services, places a strong emphasis on the role played by other sectors as illustrated in the conceptual framework (Fig. 6.2).

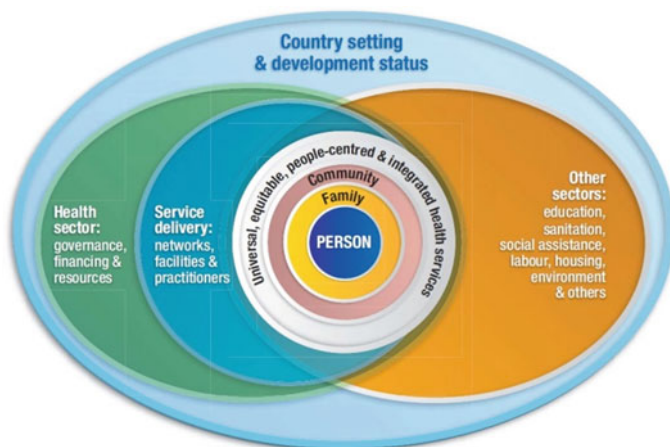


Fig. 6.2 WHO conceptual framework for people-centred and integrated health services (WHO 2016)

6.3.2 Population Health Management Approach

By contrast, the population health ‘management’ approach is a person-centred approach to meeting the needs of those with identified health- and social care needs. This approach focuses on groups of patients included in insurance plans, hospital patient cohorts, accountable-care organisations or other health- and social care organisations. In its narrowest conceptual form, the population health ‘management’ approach will focus on medical conditions with little consideration for the social or prevention dimensions. Of particular significance, here is the population health ‘management’ approach developed by Kaiser Permanente (KP) which includes health promotion and disease prevention elements. The approach was modified by the Kings Fund (UK) for the Barcelona Integrated Care Strategy (Ham 2003) to include the social dimension (Fig. 6.3).

6.3.3 Combined Population Health Improvement and Management

Some healthcare systems, by contrast, will pursue both population health improvement and population health management strategies at the same time. In this way, they collaborate with other sectors for both: improving the care of their patient population and improving the health and well-being of the wider geographical population. A further aspect of more mature systems is strong advocacy to address the upstream macro-structural determinants of health and well-being. This approach has been incorporated into the National Academy of Sciences (USA) report: *Integrating social care into the delivery of health care: Moving upstream to improve*

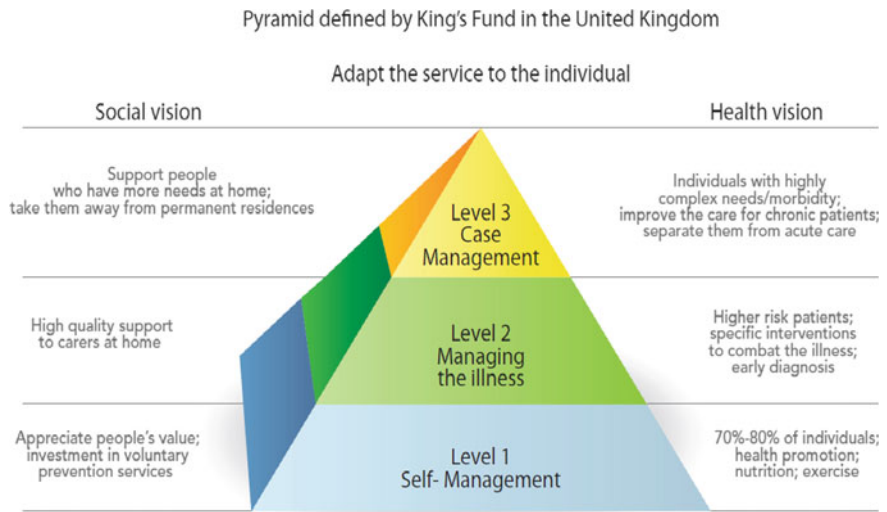


Fig. 6.3 Kaiser Permanente (KP) pyramid as adapted by the Kings Fund (UK) (Ham 2003)

the nation’s health (National Academies of Sciences 2019). The report identifies five complementary activities in the healthcare setting to facilitate the integration of social care (defined as activities that address health-related social risk factors and social needs) into the delivery of health care (Table 6.1) (Bibbins-Domingo 2019). Bibbins-Domingo (2019) further note that the activities of ‘alignment and advocacy recognise that some social needs may broadly affect a community and the most effective role for the healthcare system is to tackle these needs collectively and not just one patient at a time’.

It is becoming increasingly clear to health funders that social risk factors are impacting on their health costs as evidenced by longer length of stay, frequent representations and more complex morbidity. It is in this context that population health management systems are increasingly asking their patients about the SDOH in clinical settings.

An alternative to the top-down structural approach to the integration of health- and social care services is to adopt a bottom-up person-centred and locally driven approach that puts individuals and their families at the centre and incorporates place-based and local system change elements. Such an approach draws on the foundations of the Alma-Ata Declaration in the context of person-centred integrated health (and social) services.

An example is the *Healthy Homes and Neighbourhoods* Integrated Care Initiative in Sydney, Australia, which was collaboratively designed as part of a local district ‘whole of system’ approach to child, youth and family health and well-being. The design intentionally drew on both population health improvement and population health management approaches as discussed above. The design elements included: identification of vulnerable family cohorts; care coordination;

Table 6.1 Five categories of healthcare activities that facilitate addressing social needs applied to a transportation-related example

Activity	Definition	Transportation-related example
Awareness	Activities that identify the social risk and assets of defined patients and populations	Ask patients about their access to transportation
Adjustment	Activities that focus on altering clinical care to accommodate identified social barriers	Reduce the need for in-person healthcare appointment by using other options such as telehealth appointments
Assistance	Activities that reduce social risk by providing assistance in connecting patients with relevant social care resources	Provide transportation vouchers so that patients can travel to healthcare appointments; vouchers can be used for ride-sharing services or public transit
Alignment	Activities undertaken by healthcare systems to understand existing social care assets in the community, organise them to facilitate synergies and invest in and deploy them to positively affect health outcomes	Invest in community ride-sharing
Advocacy	Activities in which healthcare organisations work with partner social care organisations to promote policies that facilitate the creation and redeployment of assets or resources to address health and social needs	Work to promote policies that fundamentally change the transportation infrastructure within the community

Source Bibbins-Domingo (2019)

evidence-informed intervention(s); general practice engagement and support; family health improvement; placed-based neighbourhood initiatives; interagency system change and collaborative planning; monitoring of individual and family outcomes; and evaluation (Eastwood et al. 2019a). The person-centred intervention is supported by other tiered components that function at professional and organisational levels (see Box 1).

Box 1: Healthy Homes and Neighbourhoods Key Features (Eastwood et al. 2019b)

Healthy Homes and Neighbourhoods

The Healthy Homes and Neighbourhoods Integrated Care Initiative uses a stratified population-based approach to address the needs of families who are experiencing adversity, whilst supporting parallel interventions for families more generally. The approach to identifying the most vulnerable families who are disconnected from key services has been developed using existing perinatal risk-assessment systems, developing new cross-agency assessment and

referral pathways, and improved hospital recognition of the needs of families using an e-health solution.

The initiative has the following key features:

1. Multiple core and non-core agencies **working together over a sustained period of time** (i.e. 5 years) with families with complex health and social needs
2. Co-design and co-production of the initiative in **partnership** with families and service partners
3. **All the needs of enrolled families are in scope** for the intervention, including housing, employment, income support and legal advice
4. An **early intervention and public health approach** to interrupting cycles of family disadvantage, poor health and psychological trauma
5. A **focus on efficiency** through the maximum use of, and leverage from, existing family, societal and government resources, including Medicare scheduled services
6. Use of **evidence-informed integrated care methods** by service partners, including family case conferencing, and ‘wrap-around’ care delivery
7. Encouraging families to have a **‘health home’** for all their health needs and supporting progress towards self-efficacy
8. **Providing a supporting structure to general practice** providers to care for families that are often seen to be ‘too difficult’
9. Development and implementation of **shared assessment tools and referral criteria**
10. Implementation of **family assessment and engagement tools** that can be used over the long-term to monitor the health and well-being of family members.

A central element of the initiative is targeted long-term sustained cross-agency care coordination. The design acknowledges the need for significant system redesign and commitment from partners. The initial model required a care coordination team with both project-funded and partner-funded components as a means of ensuring sustainable ‘collaboration’. The initiative also includes local elements through deliberate recruitment of families and service partnerships in the City of Canterbury and City of Sydney local government areas. This last component enabled the development of ‘demonstration-site’ place-based partnerships with local general practice, schools, family support agencies, local government, religious and faith-based organisations and community members.

6.4 Integrating Health and Social Care for Individuals

Coordination between health and social services reflects the general challenges found within all forms of integrated care that seek to bring together professionals, services and organisations from different backgrounds and sectors around the needs of individuals and their families (Hujala et al. 2017; Auschra 2018; Seaton et al. 2018). Research highlights that the particular contexts and cultures of health- and social care services result in such general challenges being commonly experienced in distinct ways (Petch 2012; Cameron et al. 2014; Miller et al. 2016). The distinctive challenges within health- and social care integration include:

- (1) Professional rivalry between social workers and doctors based on the perceived conflicts between their traditional philosophies of care (i.e. ‘medical’ and ‘social’ models). Furthermore, these professions are dominant in their own sectors and therefore not familiar with their professional judgements being challenged by another profession of ‘equal’ standing.
- (2) The high proportion of staff within social care who do not have the formal status of a ‘registered professional’. This can lead to them having lower status to more professionalised health colleagues and excluded from decision making, despite often having a detailed knowledge of a person and their day-to-day life.
- (3) Healthcare receives more funding than social care. This results in disparities in technical capabilities, standard of facilities and accommodation and overall workforce capacity. Health care is often more able to lead on integrated care initiatives due to their greater infrastructure. This can result in their perspective dominating the objective setting and implementation process.
- (4) Public interest in health care is greater because it is accessed by all of a population at some point in their life, and its professions have traditionally been held in high esteem. This leads to its prioritisation by politicians over the less popular social care sector which is accessed only by a proportion of the population, is not always seen favourably, and which supports stigmatised and excluded groups.
- (5) Social care services are delivered by a myriad of agencies from private and non-governmental organisations. The fragmentation of the sector can give it less influence than the large provider organisations within health care such as hospitals and the powerful professional colleges.
- (6) The policy development and governance of health- and social care services commonly fall under different parts of government and/or public entities. Social care is commonly coordinated at a local level while health care is often led nationally. Performance targets and inspection regimes may be therefore different leading to organisations focussing on their own sector’s objectives and requirements to the detriment of a local system as a whole.
- (7) Reflecting in part the financial differentials, there has been much less research in social care than health care, and in particular clinical care and pharmaceuticals. This can result in healthcare interventions being seen as better supported by evidence and therefore more worthy of investment than the under investigated social care support.

There are important consequences for individuals and their families from direct health- and social care services not collaborating. Social care support is often central to people being discharged from hospital following admissions for physical and/or mental health crisis and/or planned treatment. A lack of coordination results in people having to remain longer in such settings, which can result in frustration and uncertainty for them and their informal carers. Similarly, those with long-term physical and/or mental health conditions are admitted into crisis and/or hospital care because their social issues have not been addressed. Difficult social contexts can result in people's health deteriorating and reduce their resilience to cope with their health condition. Particular difficulties in relation to integration between health and social care are experienced at times of transition. For example, when young people with disabilities and/or mental health difficulties are moving into adulthood, this will often involve them leaving behind the health, education and care services that have supported them through childhood and adolescence to access an unfamiliar range of support. This process commonly involves them also losing their care coordinator and this further complicates navigating this new environment. Social work's central role in many countries in relation to safeguarding means that good collaboration with health professionals is vital to identify concerns at an early point and ensure that interventions are in the best interest of the child or young person.

Box 2: Example of Benefits of Better Integration Between Health and Social Care (Cornell et al. 2020)

Social care within Patient Aligned Care Team

The Veterans Health Administration describes itself as America's largest integrated healthcare system, providing care at 1255 healthcare facilities, including 170 medical centres and 1074 outpatient sites of care of varying complexity (VHA outpatient clinics), serving 9 million enrolled Veterans each year (<https://www.va.gov/health/>). The Patient Aligned Care Team (PACT) was launched by VHA in 2010 to introduce the primary care medical home model to improve patient-centredness, coordination and continuity of care. PACTs involve 'teamlets' of professionals including primary care physician, nurse, clinical associate and administrative staff member supporting around 1,200 patients. Social workers were seen as bringing expertise in responding to psychological needs of veterans, supporting informal carers, arranging support in the home and addressing wider social issues including isolation and housing. VHA recognised that many of the PACTs in rural settings did not include social workers and therefore introduced a programme to recruit social workers for these teams in 2016. Between 2016 and 2019, ninety-five social work positions were created which enabled ninety-three primary care sites to have social workers present on a full- or part-time basis. Cornell et al. (2020) undertook a study of the programme which exploited the staggered implementation to identify comparison groups (i.e. early implementers and late implementers). They found that visits to emergency departments by veterans decreased following the introduction of a new social

worker. This appeared to be due to reductions in the number of visits connected with preventable causes such as non-urgent concerns and those that could be addressed through more thorough management of their conditions. In addition to the reduction in use of costly hospital resources, they highlight that veterans having better access to social workers could result in other benefits including reducing stress, improved coordination and wider social supports.

Fragmentation between health- and social care services also has major implications for efficiency and productivity. Acute health services are generally more expensive than community-based social care and therefore avoiding unnecessary admissions and securing timely discharge has become a major focus for governmental policy. Similarly, insufficient collaboration can result in people becoming admitted to long-term institutional settings following a time of crisis. Hospitals can apply pressure for patients to be discharged as soon as they deemed medically fit in order to free up ward capacity. This can result in older people moving into care homes on a permanent basis when a longer period of rehabilitation could have enabled them to return to a community setting. Such inefficient use of resources due to fragmentation between health and social care is also recognised for other populations. For example, people with a learning disability and/or complex mental health difficulty may be subject to long admissions to assessment and treatment facilities due to a failure of community-based health- and social care services to provide intensive support during a time of crisis (Miller et al. 2018).

This combination of improving outcomes for people and families and ensuring that resources are used more effectively has convinced policymakers that better integration between health- and social care services should be a priority. This has only heightened with ageing demographics and increasing proportion of populations with multiple long-term conditions. Reflecting the distinct challenges outlined above and our understanding of how to support integrated care in general, it is evident that better integration between health and social care will require change at all levels of the health and care system. Whilst often seen as an amorphous whole, health and care policy in the UK has been devolved to the home nations (i.e. Northern Ireland, Wales, Scotland and England) which lead to differences in how they frame similar challenges for their populations and the solutions that they propose (Kaehne 2017; Miller 2019). Health- and social care integration is though a common aspiration, and all of the home nations have introduced over the past decade a similar blend of policy and practice approaches to facilitate more coordinated care (Table 6.2). These include system-level outcomes and population-based planning, integrated organisations and/or partnership boards, multidisciplinary health- and social care teams, an overall narrative of community based and person-centred care and addressing functional barriers such as siloed budgets and workforce planning. Some progress has been made, for example in relation to slowing increasing rates of hospital admissions within the UK regions

Table 6.2 Examples of development to promote integration between health and social care in the four home nations of the UK

	Scotland	Northern Ireland	Wales	England
System	National health and well-being outcomes	Integrated Care Partnerships	National Outcomes	Integrated Care Systems
Organisational bodies	Lead Agency for delivery of health and social care	Joint health and social care trusts	Regional Partnership Boards	Transfer of public health to Local Authorities
Professional	House of Care	MDTs in Primary Care	Primary Care Clusters	Multi-Speciality Community Providers
Service	Lead professionals	Family Support Hubs	Integrated Family Support Teams	Integrated personal budgets
Normative	Live longer healthier lives at home (or in homely setting)	New model of person-centred care	Healthier and happier lives through whole system approach	<i>"I can plan my care"</i> I statements
Functional	Pooled budgets for social care and primary care Workforce Plan	Patient e-Portal Electronic Patient Record	National Transformation Fund	Better Care Fund Health and Care Record Exemplars

Source Miller (2019)

that adopted multi-speciality community providers and reducing delayed transfers of care in Scotland. However, it is clear that despite all of the attention and investment, there remains fundamental divisions and more must be done to achieve sustained integration between health- and social care services (Box 3).

Box 3: Examples of Criticisms of the Extent of Health- and Social Care Integration From National Audit Reports in the Home Nations (UK)

"The Integrated Care Fund has helped to bring organisations together to plan and provide services The fund has provided an impetus for partners to develop integrated services and to move to joint funding arrangements in the context of wider policy and legislation ... [however] the overall impact of the fund in improving outcomes for service users remains unclear, with little evidence of successful projects yet being mainstreamed" (Welsh Audit Office 2019).

“The HSC system continues to be under mounting pressure and the costs associated with maintaining existing models of service continue to increase at a pace which cannot be sustained within the budget available. There is a clear need for successful transformation of service delivery models ... However the successful delivery of this vision will require new ways of working, including with partners outside of HSC Trusts” (Northern Ireland Audit Office 2018).

“Integration Authorities (IAs) have started to introduce more collaborative ways of delivering services and have made improvements in several areas, including reducing unplanned hospital activity and delays in discharging people from hospital ... Financial planning is not integrated, long term or focused on providing the best outcomes for people who need support ... [making] it difficult for IAs to achieve meaningful change” (Audit Scotland 2018).

“[Government] expectations of the rate of progress of integration are over-optimistic. Embedding new ways of working and developing trust and understanding between organisations and their leaders are vital to successful integration. This can take many years because the cultures and working practices in the health and local government sectors are very different” (National Audit Office 2018).

6.5 Integrating Health and Social Care Through the Workforce

When approaching integrated care from a medical perspective the workforce considerations focus often on interdisciplinary teams where the members are subspecialty doctors and nurses with perhaps some consideration of the allied health professions that support treatment modalities of care. Professional and regulatory agencies provide in these circumstances clear clinical governance regarding matters such as accreditation, scope of practice and clinical standards. To address the complex social needs of patients and families, there is a requirement for collaboration beyond the traditional healthcare teams to include staff from social care services, housing, schools, residential institutions, correction facilities, local government and community-based organisations. The ability of these interdisciplinary teams to function effectively is dependant of a wide range of factors many of which relate to workforce capacity, relationships and governance. Furthermore, it is important to recognise that it is not only those working in the frontline who have to adapt their practice to achieve better integration. Those who are responsible for the planning, funding, policymaking and managing of the health- and social care sectors must demonstrate new collaborative behaviours in order to address these long-standing and embedded barriers and missed opportunities to address inequalities.

6.5.1 Inter-Professional Competence

As highlighted above, there are long-standing challenges in relation to the ability of health- and social care staff to collaborate constructively due to professional tensions and/or perceived differences in status and expertise. One issue is the willingness of this workforce even to consider such engagement on the basis that it is out of their area of concern and/or they are sceptical that it will lead to any benefit. A second issue is that even if they do recognise the importance of working better with those from the different sector they may not have the underlying competence to do so successfully (Xyrichis and Lowton 2008; Mangan et al. 2015; Carpenter and Dickinson 2016). This is despite the underpinning values, skills and knowledge necessary for health- and social care integration to be well recognised at a practice level and receiving greater attention for those within management and leadership roles (see below) (CIHC 2010; IPEC 2016; Miller and Stein 2020).

One approach to support the development of such competencies is through inter-professional education (IPE) in which health- and social care professionals learn alongside and from each other (Baker 2010; Carpenter and Dickinson 2016; Miller et al. 2019). IPE is becoming more common within education settings delivering qualifying/post-qualifying programmes and within on-going professional education. Often though, this is limited to health professionals and further limited to formal ‘professionals’ rather than involving those with other roles and backgrounds. Reflecting the wider context of integration between health and social care, such limitations can reflect a lack of awareness from educators rather than an opposition to opening up training wider as such. Engaging multiple professions in a learning process can be extremely challenging, and this is amplified if (as can be the case with social care) the students or staff are based in or employed within different colleges or organisations. There is also an issue of appropriate design and quality of delivery in relation to inter-professional education with health and social care (Mertens et al. 2018). Simply getting sufficient funding, institutional agreement, timetable co-ordination and faculty support can be enormously challenging. This can then result in insufficient capacity to develop learning opportunities that will facilitate changes in professional behaviour into the long term despite the enablers of inter-professional education being recognised in research and practice (Table 6.3).

6.5.2 Professional Accountabilities

Practice governance frameworks are well developed within most of the sectors that will partner in the integrated health- and social care setting. The funding mechanisms will usually include requirements for accreditation against national and international standards that include workforce-related standards. Complications begin to occur when health practitioners are employed by non-health organisations where supervisors are either not from a health background or not from that specific clinical speciality. Clinical supervision arrangements may not be sufficient to

Table 6.3 Enablers of inter-professional education

Aspect	Description
Involved patients	Patient stories, home visits, co-designed, patient led
Holistic focus	Multi-professional assessment, patient experience, determinants of health
Practical orientation	Supporting individuals. Undertaking shared project, community action
Multi-modal	Lectures, on-line learning platforms, group discussions, team tasks, collective reflections, observations
Multi-professional	Professions, disciplines, agencies, sectors
Robust evaluation	Formative and summative, impact, mixed methods

Source Miller (2019)

adequately support that staff member. Similar situations occur within the health sector when a sub-speciality practitioner is deployed away from their core team (i.e. community social worker in a dental hospital). Even more difficult challenges can occur where non-licensed social care staff work in close partnership within healthcare teams. That workforce includes: (1) community workers and community health workers; (2) case managers, care coordinators and care navigators; (3) home health aides and personal care aides; (4) family caregivers; and (5) other professionals such as community lawyers (Table 6.4).

Apart from the legal profession, many of the above categories of workers are not registered by statutory professional regulatory agencies. Consequently clinical governance concerns are often raised in relation to scope of practice. This then becomes a barrier to full integration of the social care workforce into transdisciplinary care teams. It is also used as reason for not sharing both personal and clinical information even when the practitioner is closely involved in a shared-care relationship with a patient.

6.5.3 Information Sharing

Information sharing among agencies and practitioners is essential for the provision of high quality health and social care. As noted above modern high-quality health care has moved towards utilisation of integrated systems that include multidisciplinary teams, bio-psycho-social interventions and follow-up care often by other professionals and agencies. Such approaches are considered to be part of an evidence-informed ‘duty of care’. But an approach that aims to act in the best interest of patients is also in tension with the principle of respect for patient autonomy.

Central to clinical integration is the sharing of clinical information between providers of care to patients. Some of those providers will be known to the patient whilst others (i.e. clinical supervisors, pathology and imaging services) will not. A further complexity is that some practitioners may not be considered members of the traditional healthcare team (i.e. school educational psychologists, security staff,

Table 6.4 Non-licensed social care workforce examples

Category	Description
Community Health Workers	Community health workers (CHWs) provide linkages among health, social services and the community. Often recruited from the communities they serve CHWs work in health systems, social service agencies and community-based organisations. They are engaged in awareness, assistance and advocacy activities
Social Service Navigators, aides and assistants	Social service navigators, aides and assistants and also trained volunteers often work outside of the healthcare sector in awareness, assistance and advocacy roles in social service agencies and community-based organisations. Examples include housing and transportation experts, people who work at food banks, people who provide employment assistance, outreach and enrolment workers, navigators and trained volunteers
Home Health Aides and Personal Care Aides	Within the healthcare sector, home health aides and personal care aides provide extensive social support services to assist older adults and disabled and post-acute care patients in their homes. These direct care workers have close contact with the country's most disadvantaged patients
Family Caregivers	People who provide care for their family members (family caregivers) are another critical part of the care team and provide assistance to many individuals. Because they spend time in the home, family caregivers, similar to home health aides and personal care aides, have a valuable perspective on the social needs of patients. I
Case Managers	Case managers (and care managers) work intensively with individuals with complex social needs, whether in the healthcare system or with social service agencies. They can be based in hospitals, at home care agencies, in skilled nursing and rehabilitation facilities, or with community-based organisations. Case managers also are found in social services agencies, such as foster care agencies, child welfare agencies, senior centres and homeless shelters. Often, the role of case managers is filled by licensed clinical social workers and licensed nurses
Lawyers	Lawyers who address the social needs of patients and families are increasingly being used in community-based organisations, including some federally qualified health centres, to assist patients and families with legal matters that can compromise health, such as inadequate housing or a loss of housing

Adapted from National Academies of Sciences (2019)

religious counsellors, disability support workers and practitioners working in the criminal justice sector). Thus, the provision of excellent integrated clinical care requires the sharing of clinical information with a multidisciplinary healthcare team of clinicians from across a wide range of sectors and disciplines.

With the development of digital technology, clinical information can be rapidly shared between healthcare teams, institutions and actors involved in system management and evaluation. At the agency and system levels of an integrated service system, there is also an increasing focus on personal health data integration within health care as evident by the implementation of the various forms of shared health records. The sharing of information is often problematic and is often reported as a barrier to integration of health and social services. Barriers exist for both identifiable and non-identifiable information sharing.

Cross-agency sharing of de-identified personal information is usually for advancing a shared understanding of population health and well-being and for improving the delivery of health and social services. Despite this common purpose, the sharing of de-identified information can be difficult in some jurisdictions. The challenges of sharing identifiable personal and clinical information are many. That cross-agency sharing of identifiable personal information can be for: (1) clinical care of individuals who have consented for the shared use of their information; (2) clinical care of individuals who have not consented for the sharing of their information but where the use is covered by that jurisdiction's privacy codes; or (3) protection of the individual and others as is covered in that jurisdiction's statutory legislation (i.e. mental health, child protection, public health and criminal legislation).

Each country and statutory jurisdiction will have different statutory provisions. Within New South Wales (NSW), Australia, for example, it seems clear that both the Australian Privacy Principles and NSW Health Privacy Principles make provision for clinicians to share information within the 'healthcare' team, and with closely affiliated clinicians where there has been informed consent from the patient. It is also clear that where informed consent has not been obtained, health information can be used and disclosed (shared) for the purpose for which it was collected (the primary purpose) and for other purposes that are related to the primary purpose and that are within the individual's reasonable expectations.

It seems, therefore, that multidisciplinary interagency healthcare teams can collect and share health information, without consent, provided the purpose is closely related to the primary purpose for which it was collected. Given that the holistic nature of health and social care is not always fully appreciated, the 'sharing' of sensitive information with others in the 'team' will not always be fully understood. It is, therefore, appropriate to inform patients of the nature of the 'multi-disciplinary health- and social care team' and to advise them of the practice of sharing health information among team members. The sharing of health information between health- and social care team members is an important component of the drive to improve the quality and safety of care. Barriers to such information exchange are often advanced as the underlying reasons for mishaps in the provision of care and the failure to implement change.

6.5.4 Leadership and Followership

Clinical leadership is now seen an important enabler of quality practice by health professionals (Ezziane 2012; Daly et al. 2014; Mulla et al. 2014). Such leadership builds on socialisation processes within professional training, registration and bodies and the powerful influence of peers and ‘esteemed’ colleagues. Whilst in many ways a strength of health care, clinical leadership can reinforce an isolation mentality if focussed on the preservation and status of the profession rather than the interests of individuals and their families. Professions are particularly susceptible to separatist behaviour when they perceive that aspects of their traditional scope of practice are being encroached upon, or they believe that their professional autonomy is being diluted through more shared and open decision-making (Braithwaite 2013; MacMillan and Reeves 2014). Integrated care can of course introduce both such dynamics, with multidisciplinary team structures being a common vehicle to bring together different professionals (Jelphs et al. 2016). The addition of social care to such teams can add further disruption, due to the lack of traditional professional hierarchy and/or an unfamiliarity of health professions and practice roles within social care. Similar challenges can be experienced within senior management and governmental roles with leaders familiar with their own health- or social care contexts finding it difficult to engage and influence those from an alternative sector (Miller and Stein 2020).

There is therefore a need for leaders at a clinical and senior level to demonstrate a new form of leadership. Rather than being limited to their own profession or organisation, this must instead be able to connect and inspire those within different roles and sectors (Ghate et al. 2013). Systems leadership is being promoted in other areas than health and social care, but there is increasing recognition that it is a necessary component of achieving the benefits of integration (Senge et al. 2015; SCIE 2018). There is not one model of system leadership as such, but there are common elements: system leaders are best placed to tackle ‘wicked’ issues which involve many stakeholders and uncertain solutions; system leaders work collaboratively with others to encourage a sharing of resources and creative thinking; system leaders are focused on goals of collective interest and are willing to sacrifice personal benefits to achieve this greater good; and system leaders enable those with lived experience and communities to participate in decision-making and contribute as partners (Miller 2020). System leaders at a senior level will often work through partnership structures and management networks, whereas system leaders at a clinical level will work through care pathways, multidisciplinary teams, and professional networks. Both will need a similar set of skills, values and facilitative style of leadership (Evans et al. 2016). Whilst sometimes overlooked, as important as the system leaders is the readiness of ‘followers’ who are willing to follow this new vision and alternative ways of working.

6.6 Conclusion

In this chapter, we have examined the impact of social issues on people's health and well-being and presented the argument that integration at both population-level and in delivery of direct services are necessary to achieve better outcomes and address inequalities. Different approaches to responding to social need are taken within and between countries and regions. This is influenced by macro-economic, funding and delivery structures, and also their cultural traditions of how best to care for those with social needs. Despite such differences, there are common lessons that can be shared internationally. Common challenges include: professional rivalry between professionals, perceived lower status of consumers and 'unregistered' workers, siloed funding structures; multiple agencies and performance frameworks non-incentivising integrated working. Arrangements that on paper offer a one-stop solution are not successful in isolation. The existence of a single agency for health and social care does not mean that people will experience person-centred and coordinated care. Population health improvement and population health management approaches fail due to the lack of a common vision, strong leadership and appropriate governance structures. Addressing the long-standing fragmentation between health and social care requires a fundamental shift in the recognition of professionals and those in senior leadership regarding the potential for better working between these sectors and their own contribution to achieving this in practice. Identifying what will work in a locality requires open and honest debate of the policy and practice context, including underlying assumptions about the relative merits and the historical tensions and differences that need to be addressed. Whatever arrangements are introduced, 'trust', 'partnership' and 'working in teams' will be central to the solutions.

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Integrated Community Care—A Community-Driven, Integrated Approach to Care

7

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7.1 What is ICC?

Integrated Community Care (ICC) is moving to the forefront of an international policy and practice agenda. At first sight, ICC bundles three generic concepts: ‘integrated’, ‘community’ and ‘care’. In its most rudimentary form, ICC is recognised as a much-needed and valuable expansion of the more typical notions of integrated care, with explicit recognition of the value, potential and power of communities, citizens and informal caregivers. Or, as a formula: $ICC = IC + C$. However, this is a rather shallow vision on ICC. The present chapter highlights the distinctiveness of the approach beyond a community-flavoured version of ‘integrated care’. It is an approach that takes a person’s and community’s strengths, goals and needs as a start point and focuses on tackling inequities in health (Dahlgren Göran 1991). There is a wide diversity in the landscape of ICC practices. Integrated Community Care is not a prescriptive approach, or a managerial toolbox, but rather a set of principles that wholly or partially manifest themselves in a range of existing practices and have the potential to evolve to a paradigmatic and dialectic change in the way health and care are organised.

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This chapter is structured as follows:

- (a) A broad description of Integrated Community Care in the form of a ‘root definition’;
- (b) An emerging set of ‘effectiveness principles’ to act as a compass to guide implementation of ICC;
- (c) An overview of three existing practices that exemplify the essential elements of an ICC approach;
- (d) A reflection on the link between Integrated Community Care and community resilience;
- (e) A conclusion that ties various themes together.

This chapter draws to a significant extent on findings from a series of conferences organised by the TransForm partnership (Transnational Forum for Integrated Community Care). TransForm is a joint initiative of Foundations in Europe and Canada that aims to inspire and mobilise policy-makers and practitioners to foster Integrated Community Care.¹

7.1.1 A Root Definition

The contours of the field of Integrated Community Care can be captured by formulating a phrase that synthetically captures the what, how and why of ICC:

Integrated Community Care encompasses a range of strategies to support professionals, organisations, policy-makers and members of a community in a continuous process of co-developing health, care and social support infrastructures and services with the aim to enhance the quality of life, social cohesion and resilience of a territorially defined community.

Integrated Community Care in many respects represents a paradigm shift. Certainly, ICC shares the ambition of integrated care to enhance the quality, value and experience of care, improve population health and wellbeing, and increase job satisfaction in the workforce. It also reflects the understanding that health and care services are delivered through co-productive partnerships and intersectoral and interdisciplinary collaborations. The key difference is the move beyond ‘delivery’ to genuine ‘co-creation’ with the individuals and communities that are traditionally seen as recipients.

Integrated Community Care is strongly aligned with the principles underlying the vision for primary health care (PHC) put forward by the World Health Organisation (WHO). This vision sees primary care as a foundation for a resilient, equitable and efficient healthcare system as it integrates three key functional components (UNICEF 2018):

¹TransForm initiative. Information available online: <https://transform-integratedcommunitycare.com/>.

- Meeting people's health needs through comprehensive, integrated health and care services, throughout their life course;
- Systematically addressing the broader determinants of health through evidence-informed policies and actions across all sectors; and
- Empowering individuals, families and communities to optimise their health.

Integrated Community Care builds upon the WHO vision for primary health care. ICC:

- *Goes beyond 'care'*. It is just as much about activating and reinforcing the social ties between people. ICC is an investment to *improve both health and social cohesion*. ICC views health as a public good.
- Pivots on greater integration between primary care, specialised care, public health functions, social work and neighbourhood development. Network governance is a crucial competence to continuously form new constellations of service providers that can respond to changing and spatially differentiated needs.
- *Is goal-oriented in nature, supporting people's priorities and life goals*. Such a goal-directed approach represents a more positive view on care, characterised by a greater emphasis on individual strengths and resources. This is a fundamental shift from the traditional, disease-specific, problem-solving approach.
- *Is place-based*. A place-based community is a reservoir of possibilities and assets that can be re-appropriated and replenished on an ongoing basis and leveraged in a range of societally relevant projects. Place-based governance is a participatory, empowering and trust-based alternative to a traditional model that focuses on centrally defined and measurable targets as a guarantee of accountability.
- *Assumes accountability towards a territorially defined population*. This ensures that resources are equitably and efficaciously allocated to where the most acute needs are, ensuring no one is left behind. The involvement of local actors (including local authorities) in the decision-making process is required.
- *Inscribes itself in an enabling perspective on public services*, beyond taking care of infrastructural needs and material safety to creating opportunities for community members to fulfil a larger role in society.
- *Reaches underserved and marginalised groups* to tackle social exclusion, social isolation and help overcome problems related to discrimination, stigma and violence.
- *Engages and empowers people* in local communities and thus plays a central role in valuing the position of the *informal care sector* and of *peers with lived experience*. ICC requires a dynamic, assets-based approach to community development, characterised by non-hierarchical processes, highly engaged communities and distributed leadership
- *Comes down to a continuous process of 'whole system innovation'*. ICC points towards a paradigm shift at the citizen, community and system levels. Lived experience, a shared vision on the fate of the community, distributed power and collective learning are the cornerstones of this comprehensive perspective on health and care.

7.2 Advancing the ICC Agenda

How can Integrated Community Care move from an aspiration into reality? The collection of reflections from experts and practitioners in the setting of the Transform learning journey has led to an initial set of seven effectiveness principles that provide guidance for thinking and acting towards a future in which ICC is the norm. The principles are not prescriptive but meant as a compass for those aiming to bring Integrated Community Care to life in a variety of contexts (Patton 2017).

Co-develop health and wellbeing, enable participation

1. Value and foster the capacities of all actors, including citizens, in the community to become change agents and to co-produce health and wellbeing. This requires the active involvement of all actors, with an extra sensitivity to the most vulnerable ones.
2. Foster the creation of local alliances among all actors which are involved in the production of health and wellbeing 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 (Art et al. 2007). Take people's life goals as the starting point to define the desired outcomes of care and support.

Build resilient communities

1. 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.
2. Support healthy and inclusive communities by providing opportunities to bring people together and by investing in both social care and social infrastructure.
3. Develop the legal and financial conditions to enable the co-creation of care and support at community level.

Monitor, evaluate and adapt

1. Evaluate continuously the quality of care and support and the status of health and wellbeing 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.

The next section presents three examples of initiatives that embody ICC in different ways, reflecting their specific community's context, strengths and needs.

7.3 Exemplars

Examples of ICC in action can be found all over the world. It is important to note that due to the content in this chapter being largely based on the findings from a European and Canadian initiative, the material is drawn from the ‘global North’. The ICC approach could be considered as more common and potentially stronger in the ‘Global South’ (albeit not necessarily formally described as such). This is because public resources tend to be scarcer and community assets are informally relied upon more heavily. Indeed, the WHO PHC approach is based on the experiences of Panamerican Health Organisation (PAHO) in Latin America and the community health worker programmes in Asia and Africa.

The three emblematic exemplars described below were selected to provide a flavour of the wide range of existing ICC practices. The three examples embody the ICC effectiveness principles described in the previous section, and each reflects different drivers (who initiated the project), different focuses (care provision, community building or on spatial-environmental development) and different ingredients. More information on these three examples and others can be found in the collection of ICC case studies on the TransForm website.²

7.3.1 Community Health Centres

Community health centres (CHCs) aim to meet a territorially defined group of citizens’ needs by offering accessible, high quality and integrated primary care from a biomedical, psychological and social perspective. The intention is to approach patients by taking into account their whole context: family, community, work and socio-economic circumstances.

CHCs usually bring together several healthcare providers (general practitioners/family physicians, nurses, physiotherapists, social workers, psychologists, etc.) under one roof. These professionals form part of what is commonly known as the ‘primary care’ network, and they work in an interdisciplinary team. In terms of their legal status, CHCs range from collaborative groups of organisations to single legal entities. Governance models also vary (e.g. elected members from each organisation, volunteer boards of directors or clinical management team), but they often engage community members in governance structure. This helps inform a more population health-focused approach. CHCs can be financed with an ‘integrated needs-based capitation’, whereby the centre receives an amount of money per patient on a regular basis, based on the average care needs of the population for care provided by family medicine, nurses and physiotherapists.

CHCs organise and provide care following the principle of proportionate universalism where care is qualitatively and quantitatively attuned to the goals and care needs of patients and local residents. Community health centres are well placed to

²TransForm international case studies. Available online <https://transform-integratedcommunitycare.com/casestudy/?category=international-case-studies>.