Towards people-driven care: engaging and empowering individuals, carers and families through integrated community care

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Transnational Forum on Integrated Community Care

About this paper

TransForm is a joint initiative of Foundations in and beyond Europe that aims to put the community at the centre of primary and integrated care. Integrated Community Care (ICC) recognizes people & communities as co-producers of care and seeks to examine how partnerships that engage and empower people in local communities can be developed through trans-disciplinary and cross-sectoral collaborations. The overarching aim of the Forum is to trigger the interest of and inspire policy-makers and practitioners to foster integrated community care. The ultimate goal is to mobilize change at policy and practice level by engaging policymakers, practitioners and key stakeholders in knowledge generation and sharing of case studies. The project includes a mapping of promising practices and a series of conferences and visits in Europe and beyond.

This input paper - *Towards People-Driven Care-* is designed as a briefing paper for delegates attending the 2nd Transnational Conference on Integrated Community Care in Turin, Italy on the 26 and 27 of February 2019. It is the second in a series of such briefing documents supporting TransForm's conference series. The paper is designed to equip participants with evidence on the effectiveness of key strategies that help to empower and engage individuals, carers and families to take control of their health and care needs. It examines those actions that need to happen at the micro-scale to improve care outcomes for people and how integrated community care is essential in enabling that to happen.

A note on terminology

This report uses the terms 'citizens' and 'people' as a general rule. The exception is when people actually use services, in which case you will see the term 'user' or 'patient' as appropriate.

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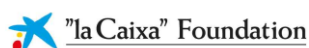
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1. Context

1.1 The compelling case for integrated community care – recap of 1ˢᵗ TransForm Conference

The first TransForm conference in Hamburg, September 2018 sought to develop a common understanding of the meaning and logic of integrated community care (ICC), illustrate the compelling case for its potential to have a transformative impact on population health and wellbeing, and examine how to successfully design and adopt innovative practices of ICC.

Lessons learned from the first conference show that progressing towards ICC requires complex and adaptive system thinking. Community development is non-linear and must deal with unpredictability and emergent causality where the interacting agents; citizens, professionals and policy makers, operate based on internal rules that cannot always be predicted. The actors adapt, interact and co-evolve across organizations and institutions and this demands new methods that incorporate how systems and communities come together as a whole. A good example of this is Obolensky's work (1), which builds upon complex adaptive system theory (2), focusing particularly on leadership. He describes organisations operating with reduced hierarchy, less management and bureaucracy and consequently improved staff engagement. This is essentially a more distributive approach to leadership.

For strategies on integrated community care to be effective, active citizenship is essential. This includes empowering and engaging individuals and families in their own health and care. This second input paper, therefore, focuses on people, their assets, and their central importance to the successful adoption of ICC in policy and practice.

More detailed information on the first conference is available here.

1.2 The call for people-driven care – the focus of this 2ⁿᵈ conference

Internationally, there has been a significant shift in public health policy towards placing people and communities at the centre of health services. For example, the World Health Organisation (WHO) emphasises the need for ensuring there is a pro-active strategy to activate, engage and empower people to achieve the best outcomes through co-productive partnerships in the *Global Strategy on Integrated People Centred Health Services 2016-2026* (3). Furthermore, the recent WHO report *Health systems respond to NCDs: time for ambition* (4), describes how people-centred and integrated health service delivery needs to be firmly embedded in strong, community-oriented primary care systems. Strengthening primary care and investing more in multi-disciplinary integrated care services is suggested to proactively enhance people's health and well-being.

The *Astana Declaration on Primary Health Care* (5) in October 2018 emphasised countries must ensure primary care:

1. empowers people and communities as owners of their health, as advocates for the policies that promote and protect it, and as architects of the health and social services that contribute to it;
2. addresses the social, economic, environmental and commercial determinants of health through evidence-based policies and actions across all sectors; and
3. ensures strong public health and primary care throughout people's lives, as the core of integrated service delivery.

However, meeting these aspirations remains elusive. Professionals are not usually proactively engaged in co-designing integrated care with people, even when this is an espoused objective of their work, and so efforts often fall short of reaching their anticipated benefits. This is in no small part because it requires a cultural change to embrace a truly people-driven approach – and culture is slow and difficult to change. But the effort may be worth it as evidence shows that when we engage and empower

people and communities, everyone's health and wellbeing can improve, and resources are allocated more efficiently (6).

Community level interventions includes more than just health and social care. It may involve investment in green spaces, housing, active transport networks, smoke free zones, traffic calming measures, road safety, the food environment, pollution and the availability and affordability of alcohol and tobacco (7). These are examples of non-medical factors that are responsible for up to 90% of health outcomes and makes a strong argument for why taking a more systemic approach to change the total environment of where people live is so important (8). The Alma Ata declaration called for population level prevention 41 years ago (9). However, contemporary health care is still mostly configured around sequential consultations and opportunistic screening procedures which do nothing to improve the local social determinants and population health.

ICC, as a core strategy within primary and integrated care, may help to unlock the necessary community and individual resources to engage and empower people to develop the skills they need to self-manage their health and wellbeing. It also entails enabling the workforce to help people achieve this.

2. What do we mean by people-driven care?

Real 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 (6). Addressing social determinants of health is a system responsibility, and as such it is essential to develop shared values and societal goals. In the Community Oriented Primary Care approach illustrated in Figure 1 below, the community is involved through identification of needs, prioritizing of problems and measuring of outcomes. People-driven care therefore requires co-productive partnerships to be developed with communities.
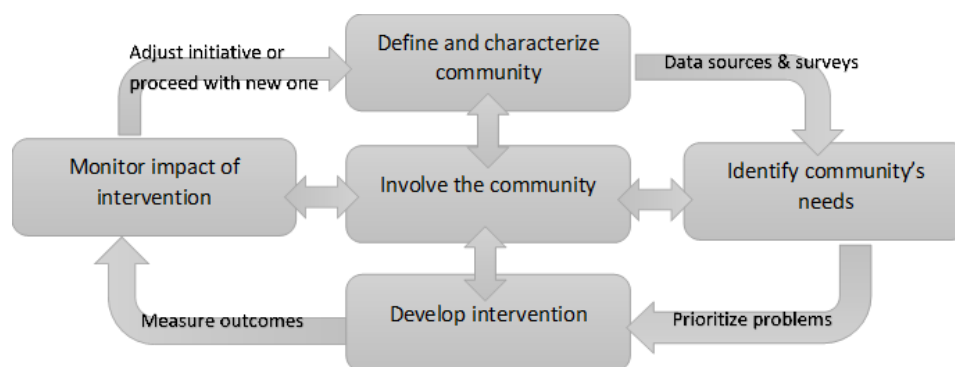
Figure 1: Illustration of the Community Oriented Primary Care approach adapted from Garr (2005) cited in Arr et al. (10).

The Community Oriented Primary Care approach supports citizens, families and communities in exerting control upon the day-to-day decisions that affect their health and care, which may results in a range of positive impacts, including better quality of care, improved outcomes and more efficient use of resources (11).

Citizen participation in health and care can also be usefully seen as a spectrum using a version of the 'ladder of participation' that Sherry Arnstein developed decades ago but that remains relevant today (12). It shows the different ways in which an organisation responsible for an activity can involve participants, be it patients or citizens. Despite ideally hovering around the top of the ladder, it is still relatively rare to find instances where the top two "doing with" approaches are successfully employed.

Most projects tend to be at the consulting/informing end of the spectrum, which may be related to uncertainty about how to involve and support a diversity of individuals and allow them to work in partnership to genuinely influence decision-making. This has exposed patient and public involvement to criticisms of exclusivity and tokenism (13).

Figure 2: The ladder of Participation (Arnstein, 1969) (12).

Co-production is about co-development of public services between professionals, people using services, their families and their neighbours in the context of an equal and reciprocal relationship. However, the value of co-production also entails a second, more fundamental partnership – one between the formal economy (comprised of public, private and non-profit sectors) and the informal economy of home, family, neighbourhood, community and civil society (14).

Arnstein's and Garr's models are intertwined in that true community development is an upstream action, that starts with providing the knowledge necessary for people to partake in creating common values and understand the community's needs as a whole. Empowerment is key to this and will be discussed in section 3.

3. What are the core strategies that engage and empower individuals and families?

The process of empowerment is the discovery and development of individual's inborn capacity to be responsible for one's own life (15, 16).

In this section we examine three essential strategies to empower individuals and families within their local communities:

1) social cohesion – this lays the foundations for empowerment because communities are the context in which people exist and we know that strong communities and relationships are essential to individual's wellbeing and can improve health outcomes;

2) goal-oriented care – in which decisions about care and treatment for people who require care and support are undertaken and led within the context of their life goals. Goal-oriented care implies shared decision making that helps to empower patients, as opposed to the traditional focus of care based on disease-management and a more paternalistic approach;

3) health literacy – a crucial tool to empower individuals, families and communities and which is a pre-requisite for integrated community care.

3.1 Social cohesion

In order to engage and empower people, it is essential to consider the context in which they live. Along with austerity and increasing inequality, isolation and loneliness are becoming common afflictions of our populations. The relationships people forge within their communities are essential to their wellbeing. Yet people often do not have the tools or the confidence to participate in their communities. This is of course not just a problem for the individuals experiencing social isolation. It is a problem for society as a whole.

A person's social networks can have a significant impact on their health. Over seven years, a largescale international study showed that those with adequate social relationships had a 50% greater survival rate compared with individuals with poor social relationships (17). Social networks have been shown to be as powerful predictors of mortality as common lifestyle risks such as moderate smoking, excessive alcohol consumption, obesity and high cholesterol and blood pressure (17, 18).

However, in the most deprived communities, almost half of people report severe lack of social support, making people who are at greater risk less resilient to the health effects of social and economic disadvantage (19). Creating the right conditions to enable people to be active members of their communities is therefore the basis for empowering people and their families.

Keynote Conference Abstract – Zoe Ferguson, Carnegie UK Trust, Associate

The Place of Kindness: Combating loneliness and building stronger communities

ICC is relationship-based, place-based and citizen-led. It is moving from needs-based to asset-based approaches. Zoe's work argues that we need to consider the relationships in places as fundamental to the context of community in which you might seek to engage and empower individuals. It also argues that we need to place more emphasis on 'care' as a value and organic, informal behaviour in communities, not merely as a professionalised service which we may invite citizens to co-produce. In this session I recap the growing body of evidence that shows that positive relationships and kindness are at the heart of our wellbeing reflect of the work of the Carnegie UK Trust to explore what we can do to help create the conditions for kindness and what gets in the way.

3.2 Goal-oriented care

Traditional disease-oriented, problem-solving models of care are increasingly being replaced with goal-oriented care, under which treatment decisions are based on a patient's expressed life goals and success is measured by the extent to which these are attained (20). Jim Mold formulated the concept in 1991 and, Boeckxstaens and De Maeseneer applied this to multi-morbidity in 2011, integrating the concept of equity (21).

The assumption is that the strategies derived from patient goals are likely to be more effective and efficient than those derived from problem-solving if the outcomes of interest are those that are meaningful to patients (22). It places the person with a need for care and support at the centre and encourages staff to work in partnership with the user, their

> *"A goal-directed approach to health care system would tie interventions directly to meaningful outcomes and provide a framework for prioritization. It would also enhance therapeutic relationships, improving adherence to therapeutic plans and reducing the practice and cost of defensive medicine. As a result, health care would be more effective, less expensive, and more humane"*
>
> - Dr Jim Mold, Concept Originator

family, carers and other service providers to deliver care in a way that is responsive to their individual needs and priorities. It is worth noting that people value their autonomy and sometimes prioritise

other life-goals than their health (e.g. giving schooling-opportunities to their children) and this needs to be respected.

There is still much to learn about goal-oriented care and how to best make it happen. A young international learning community is working on developing good practices, trainings and tools.

Goal-oriented care is about:

- gaining insight in the life-goals of the person and translate them together into care goals
- collaboration between health and care professionals through shared decision-making with the person, their family and/or carer
- setting goals that are meaningful and important to the person and their family or carer
- identification of service options, interventions, referrals and connections that meet a person's key goals
- establishing the steps to reach those goals
- creating a timeline (care plan) with start and end points, including review processes along the way
- working with other agencies and sectors (e.g. housing) through shared care planning to help realise the goals of the person

Table 1 (adapted from Murthy (2009), despite taking a clinical lens, helpfully illustrates the difference between traditional versus goal-oriented outcomes (28).

Table 1. Comparison of traditional disease-specific and goal-oriented outcomes*

Measurement domain	Examples of diseases	Traditional outcomes	Goal-oriented outcomes
Survival	Cancer, heart failure	Overall, disease-specific, and disease-free survival	None if survival not a high-priority goal; survival until personal milestones are met (e.g. grandchild's wedding)
Biomarkers	Diabetes, COPD	Change in indicators of disease activity (e.g. glycated hemoglobin level, CRP level, and pulmonary-function tests)	Non (not a meaningful outcome observed or felt by patient)
Signs and symptoms	Heart failure, COPD, arthritis	Inventory of disease-specific signs and symptoms (e.g. dyspnea, edema, and back pain)	Symptoms that have been identified as important by the patient (e.g. control of dyspnea or pain sufficient to perform an activity such as bowling or walking grandchild to school)
Functional status, including mobility	Cancer, heart failure, COPD	Usually none or disease-specific (e.g. Karnofsky score, NYHA functional classification, and 6-minute walk test)	Ability to complete or compensate for inability to complete specific tasks identified as important by the patient (e.g. ability to get dressed without help)

*COPD denotes chronic obstructive pulmonary disease, CRP C-reactive protein, and NYHA New York Heart Association

The most common health-related goal areas are (29):

1. Prevention of premature death and disability
2. Maintenance and enhancement of current quality of life
3. Optimization of personal growth and development
4. A good death

Nowadays, life-goals tend to be more about being able to function (with the International Classification of Functioning enabling us to register these dimensions) as about social participation.

Shared decision-making and personalised care

Shared decision making (SDM) is an evidence-based approach that helps to achieve goal-oriented care. It is an interactive process in which users, their family and carers, in collaboration with their professional health and care provider(s), choose the next action(s) in their care path following analysis of possible options and of their own values and preferences. Shared decision-making is for patients that are at the crossroads with an array of options, all with uncertain outcomes, including not taking action, to choose from. Flexibility and openness about the range of available options is often necessary. On one side, providers bring evidence-based knowledge of the different options risks and benefits. On the other, the patient brings knowledge of his or her life-goals. The process should happen in a context of understanding, trust, empathy, and equality. It requires a cultural change in how we speak with patients from 'what's wrong with you?' to 'what matters to you?'.

When interactions are needed in different settings and timescales with multiple professionals, a trained professional can accompany the patient throughout the path and provide support as a decision coach or navigator. This is often the task of a Community Health Worker (23). To help community health workers detecting and involving people in their care that otherwise are hard to reach, technology can act as important tools. For example, through mobile, online and other remote technologies, people with mental disorders can be provided with recovery support, online self-help programmes and programmes for substance misuse (24). In home care, technologies can help foster community-based independence for individuals (25).

When people feel in control of their health and wellbeing through being involved in decisions about their care, they tend to shape the care so that it fits in with their life, preferences and goals. Evidence shows that people who are involved in decisions about their health and care tend to report (26, 27):

- greater independence and satisfaction with the services they receive
- experience less regret about the decisions they have been supported to make and are more likely to say that the decision made was most appropriate for them
- make fewer complaints than those who were not involved.

Approaches such as shared decision making reduce unwarranted variation in care by ensuring that all decisions are informed ones - based on personal preferences and taking into account the risks and benefits of the available options and the goals or outcomes sought (26, 27).

Personalised care assessment and planning is also an important part of goal-oriented care. It is about having a single assessment process examining both the health and social care needs of the patient with long term conditions and their family, but also their personal goals and aspirations. A recent Cochrane Review found that personalised care and support planning made small but positive improvements in aspects of physical and psychological health and can support people with LTCs with self-care practices and increase levels of self-efficacy (28). The process is an iterative one and involves setting objectives (clinical ones as well as life-goals), developing an action plan and monitoring progress so that services are responsive to the needs of patients as individuals (29).

3.3 Improving health literacy

Strengthening health literacy is supporting people in developing their key cognitive and social skills, especially those that determine their motivation and ability to gain access to, understand and use information in ways which promote and maintain good health. Poor levels of health literacy are extremely common, and it affects everyone, not only the poor. Nearly half of all adults in the eight European countries tested have inadequate or problematic health literacy skills that adversely affect their health (30). Weak health literacy competencies have been shown to result in less healthy choices, riskier behaviour, poorer health, less self-management and more hospitalization. It is associated with health inequalities and is more common in low income and minority ethnic groups, immigrants, undocumented people, those with fewer years of education, and older people (31). A review by Stormacq and colleagues (2018) confirmed that health literacy can be considered a modifiable risk factor of socioeconomic disparities in health. Therefore, enhancing the level of health literacy in the population or making health services more accessible to people with low health literacy helps to achieve greater equity in health (32).

Mass media campaigns or targeted educational packages and lifestyle programmes (e.g. supported by schools, care professionals, e-health) are common in many countries and they enable people to be more aware of their health conditions and control risk factors, provided their living conditions enable them to do so. Strategies that encourage lay, parental and family-led advice and support in local communities have also been adopted. The evidence for positive benefits is strong and includes enabling people to better manage their health conditions and control risk factors associated to changes in lifestyle (33, 34).

Health literacy is an asset for individuals and communities. It helps people be more resilient, and active in improving their own health: for example, by adopting healthier lifestyles or demanding their rights as patients as well as taking action to improve health in the community. It is also an important form of social capital where a positive cycle is created - communities benefit from the health literacy of their members, while members benefit from the resources available in the community. The WHO publication *The Solid Facts* (2013) recognizes the following key attributes of a healthy city (35):

- Recognises at the highest political level the importance of becoming and remaining health literate and gives this priority through policies and interventions;

- Strives systematically to improve the health literacy of its people, its communities, various social groups and its institutions and services;

- Has leaders who understand the high relevance of health for the well-being of the city overall and the need to continually invest in and enhance the social assets of the city, including health literacy, community resilience, community empowerment and participation and social networking;

- Is committed to inter-sectorial work across government because decision-makers in many sectors understand the high relevance of health and seek health co-benefits and synergy in their policies in cooperation with the health sector;

- Provides individuals and communities with skills and knowledge because healthy people and communities are one of the key assets of cities;

- Aids citizens in navigating through health, education and social service system, making the healthy choice the easier choice in settings under city jurisdiction;

Following a systematic review of existing conceptual frameworks, Sørensen and colleagues (2012) developed a model integrating medical and public health views of health literacy (please see Figure 3) (36). It describes the main dimensions of health literacy (represented in the concentric oval shape in the middle of the figure), and of a logical model showing the proximal and distal factors which impact on health literacy, as well as the pathways linking health literacy to health outcomes.
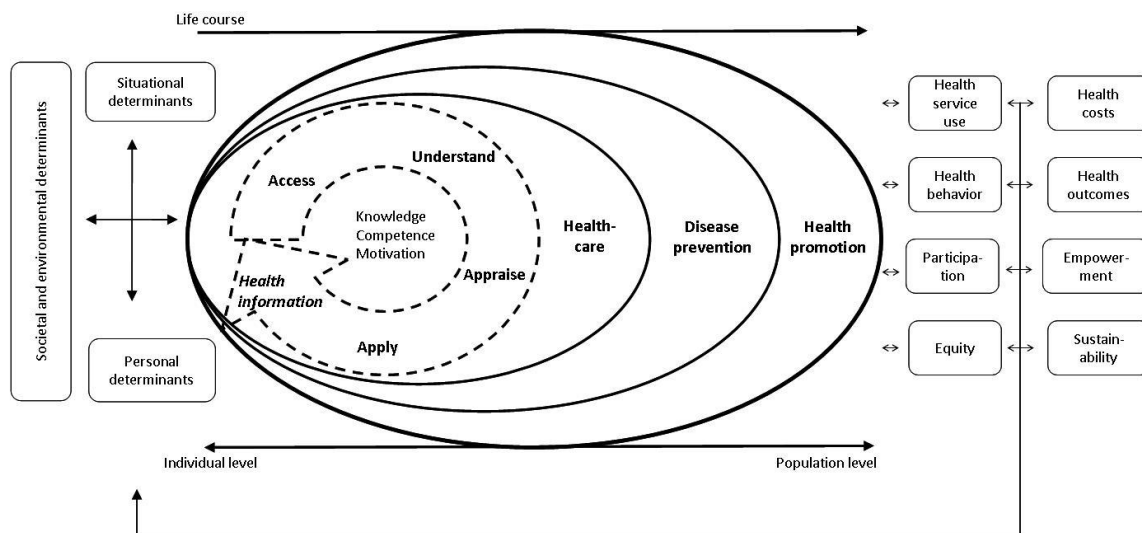
Figure 3. Sørensen and colleagues' Integrated model of health literacy.

The model can serve as a basis for developing health literacy enhancing interventions and provide a conceptual basis for the development and validation of measurement tools, capturing the different dimensions of health literacy within the healthcare, disease prevention and health promotion settings.

Recent recommendations for advancing health literacy are shifting focus of health literacy research from examining patient-level skills and deficits to more cross-cutting studies that include individuals and populations as well as health professionals and health systems (37). Adding another layer to Sørensen and colleagues' model, the "health literacy social ecological model" (HLSEM) presents a multilevel strategy emphasizing patient engagement in a supportive environment at the institutional, community and policy level (38). Taking an ecological approach could lead to more sustainable changes over time by creating supportive environments for people as they access and seek to understand health information, interact with health professionals, and move through their community and organizational contexts. The HLSEM supports environments that encourage, foster, and sustain citizen engagement, because authentic engagement relies on the ability of a person to obtain, understand, use, and communicate basic health information (38).

Keynote Conference Abstract- Don Redding, Director of Policy and Partnerships, National Voices, a coalition of national health and social care charities

Mobilising the community as an asset: what do individuals, carers and families value in supporting their health and wellbeing?

This session will present evidence on what people value as important in supporting their health and wellbeing, recognising individuals are the best integrators of their own care; and offer insights on how to best mobilise the resources in the community to achieve this.

Don will also discuss the recent NHS England Plan *Universal Personalised Care: Implementing the Comprehensive Model* and what needs to happen for it to be implemented successfully. This is essentially a rollout of a new comprehensive model for person centred ("personalised") care that could potentially be profound for people with the highest burden of ill health and lowest "activation", who have most to gain. Personalisation should be seen as a central mechanism in the tilt towards integrated primary and community care, that aims to equip, support and empower

people to manage their health and health conditions successfully enough to stay away from inappropriate urgent and emergency care. Health literacy is of course a pre-requisite for success.

4. Workforce and informal caregiving

4.1 Workforce of the 21st century

Recruitment and retention of health and social workers are a challenge for health and care systems worldwide and there is a need for the workforce to be re-designed and better equipped to respond to diverse and complex needs of people and communities (39). The WHO report: *Building the primary health care workforce of the 21st century* describes a need for health workers to approach patients, citizens and communities differently, be more open to working in teams, use data more effectively and be willing to innovate in their practice. The WHO and the Global Forum on Innovation in Health Professional Education have suggested policy options and interventions to include (40):

- Health workforce recruitment (including social attitudes, person-centredness, etc)
- Interprofessional training from first years onward, including in goal-oriented care and community oriented primary care
- Interdisciplinarity
- Early exposure to primary care and to the impact of social determinants of health
- Early contact with socially disadvantaged groups
- Multi-professional teams working across organizational boundaries
- Improving working conditions and compensation mechanisms
- Taking an assets-based approach to engaging community workers and volunteers
- Investment in effective leadership and management to support the development of community-based teams
- Ensure that national workforce planning covers both health and social care.

A recent NHS review, *Shifting the centre of gravity - Making place-based, person-centred health and care a reality* found many examples of workforce development and flexibility, including (41):

- new joint roles to support integration, such as:
  - Care coordinators
  - Integrated community teams
  - Advanced nurse practitioners
  - Generic skills training across multidisciplinary teams (MDTs)
  - Discharge to assess pathway
  - Integrated social care night service
- more posts jointly appointed – such as public health or adult social care leaders appointed across local government and health organisations
- leadership and supervision to manage MDTs
- engaging the workforce in designing and implementing new approaches
- shared professional practice and professional development, such as all front-line staff being skilled in person-centred care
- deploying staff as needed across a system and connecting professionals through primary care networks
- health and care systems sharing recruitment, selection, induction and training.

Keynote Conference Abstract – Anne Wojtak, Adjunct Faculty, University of Toronto

Preparing the workforce to be a partner in integrated community care

As healthcare systems around the world shift towards increasing integration of health and social care systems, we need to rethink how we recruit, educate and support our leaders and staff to be successful in this environment. Traditional leadership education programs are not sufficiently focused on developing the skills and behaviours for effective leadership of complex adaptive systems. This session will include evidence from the literature on core leadership competencies and behaviours (e.g. distributive leadership) for integrated systems of care and engage participants in a discussion on leadership development, challenges in shifting our leadership focus, and the implications for leadership and management recruitment and support. We will also discuss the current status of education and support for front-line clinicians with respect to new competencies required for working in collaborative care environments and improving interdisciplinary collaboration. Finally, the capacity of home care and the need to value informal caregiving and peer support will be discussed.

4.2 Informal caregiving

This is a sector that tends to be underappreciated in terms of its potential to support people and/or to provide care. ICC needs robust policy responses that recognizes informal caregivers as important members of the care workforce.

Informal care is not handled by the market and has no price tag. Consequently, making monetary comparisons with formal care is only possible to a certain extent. In a 2006 measure of the magnitude of informal care in Germany, Schneider (2006) estimates that 7% (4.8 million) of the German adult population are care providers, which corresponds to 4.9 billion hours of informal care. Substituting this informal labour was estimated to require over 3 million full-time employees and, depending on wages, between €30 and €60 billion in salary (42). However, despite the prevalence of informal caregiving, OECD reports that the affected labour force is seemingly small because caregivers are less likely to have a paid job (43).

Given informal caregivers are such a significant resource in health and social care systems and asymmetrically positioned between men and women, improving our understanding of caregiving experiences and outcomes is important. The Lifelines informal care add-on study (Lifelines ICAS) was initiated within the Lifelines Cohort Study to cover the large heterogeneity in the Dutch caregiver population and to investigate the complex interplay among the characteristics of the caregiver, care recipient, and care situation and positive and negative caregiver outcomes (44). The average age of caregivers was 53 years and 75% were female.

Even though the individual outcomes on employment and health seem rather small, the literature suggests that the effects of caregiving on those providing care are mostly negative. Evidence shows that most caregivers are not well prepared for their role and provide care with little or no support (45). Emotional, mental, and physical health problems arise from the often complex task of caring for people with chronic conditions, the frail and/or the disabled. Caregivers tend to show higher levels of depression, stress and anxiety; as well as poorer physical health. Hence, many caregivers provide care while suffering from poor health themselves (46). Given the gender imbalance in caregiving, these negative impacts disproportionately affect women.

A good example of how informal caregivers can be strategically involved is the 'caring neighbourhoods' developed in Flanders for example, the *Active Caring Neighbourhood* platform is a cooperation partnership where the partners wish to develop a neighbourhood-oriented care organization in a metropolitan context so that elderly people can remain living at home comfortably and independently

as long as possible (47). The emphasis here is on reinforcing self-reliance, informal care and developing informal neighbourhood care networks.

The Change Foundation in Canada developed a Caregiver Wishlist which illustrates the advantages of engaging patients and family caregivers in the healthcare team, as well as small things that healthcare providers can do to improve the caregiver's, and ultimately the patient's, experience. The aim is to spark transformation and a co-designed approach to patient care, including family caregivers in each step of the patient journey. The main 'wishes' identified included:

- better communications
- caregiver identification
- assistance with system navigation
- respect and empathy from healthcare providers
- discharge training
- diagnosis and journey

4.3 Peer support

Beyond families and carers, wider social support, through peers and volunteers, is extremely powerful in supporting people with long term conditions. Peer support is "offering and receiving help, based on shared understanding, respect and mutual empowerment between people in similar situations" (48). There is evidence that a flexible, proactive peer support program, in this case provided by community health workers, can reach over 90% of "hard to reach" groups who all too often fail to get the clinical and health promotion services they need (49).

Key functions of peers and volunteers can be described as (17):

- Assistance in daily management such as pursuing care objectives developed with clinical team
- Social and emotional support to encourage management behaviours and coping with negative emotions
- Linkage to clinical care and community resources

The core principles in peer support include: mutuality, reciprocity, a 'non-directive' approach, being recovery focused, strengths-based, inclusive, progressive and safe (50).

Overall, studies have found that peer support: decreases morbidity and mortality rates; increases life expectancy; increases knowledge of a disease; improves self-efficacy; improves self-reported health status and self-care skills, including medication adherence; and reduces use of emergency services (51). Providers of peer support can often feel empowered in their own recovery journey (52) have greater confidence and self-esteem (53) and a more positive sense of identity, they feel less self-stigmatisation, have more skills, more money and feel more valued (54). There is a risk, however, arising from transferring increasing responsibility to lay people while at the same time reducing the public welfare budget. This needs to be considered and managed.

5. Issues and challenges for policy makers to consider

Preventive efforts to tackle environmental risk factors and social and economic determinants of health request capital investments and health and social care system reforms. However, it is difficult for policy-makers to make decisions when robust evidence for effectiveness of population level interventions is missing and there are no clear, short term political gains.

Many countries internationally have begun to recognise the need to take a more population-oriented approach that promotes person-driven care locally, regionally as well as nationally. This trend recognises that if we are to improve people's health and wellbeing then this must be through action within the communities which we live, and which address the wider determinants of health, and our health behaviours and lifestyles. Plans to promote integrated community care, from the promotion of

integrated care systems in England to global strategies for their development espoused by the World Health Organisation, recognise that bold and new approaches are necessary.

Yet, for the most part, actions to effectively engage and empower people and communities has remained somewhat separate to innovative strategies and reforms in the provision of care and services. As a result, public health interventions have often tended to operate in separate silos to traditional care provision and the voice of people and communities is often lost. People-driven care implies the need to raise awareness of the societal value of good health, recognising the importance of community-based social networks and the benefit of focusing on both health and wellbeing.

Over the course of TransForm's conference series, policy-makers are being asked to examine the role of policy and policy-making to contribute to our understanding of what can be done to provide an enabling policy architecture that supports local adoption of integrated community care in practice. In this second TransForm conference specifically, we set out to explore how people can be empowered to make the most of their diverse perspectives and resources. Key questions to be explored in Turin include:

- What competencies are necessary to support professionals and decision-makers in working in this new environment?
- How can policy makers enable the workforce to take the time to have the important conversations on goals and priorities and to understand their patients/ users/families so that it becomes a normal part of planning and providing good care (funding models)?
- How to support the establishing of effective mechanisms to enable all concerned to obtain and share the right information for all relevant parties to empower citizens and respond adequately to their needs?
- While citizen empowerment may be policy-makers preference, implementation is dependent on key stakeholders (e.g. physicians) being on board and this is not always the case – what can we do to make sure we're all on the same page?
- How can the role of informal caregivers be maximised without overburdening them?
- How can (following the WHO-Astana Declaration) strengthening primary care contribute to more integrated approaches to health and wellbeing of individuals and communities?
- How to increase social cohesion and solidarity as the base for a resilient care system?
- How can we help to unlock the necessary community and individual resources to engage and empower people to develop the skills they need to self-manage their health and wellbeing?

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