Building stronger communities through Integrated Community Care

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**About this paper**

The input paper ‘Building stronger communities through Integrated Community Care’ is designed as a brief to delegates attending the 3rd Transnational Conference on Integrated Community Care in Vancouver, Canada 2-4 October 2019. It presents the background information and relevant evidence for delegates to understand the many ways communities can influence our health and wellbeing, including an examination of how communities must respond to different cultural contexts.

**Transnational Forum for Integrated Community Care** (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 and communities as co-producers of care. It 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 mobilize change at policy and practice level by engaging policymakers, practitioners and key stakeholders in knowledge generation and sharing of promising and best practices.

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1. Preliminary learnings on Integrated Community Care

The first two TransForm conferences sought to develop a common understanding of the concept of integrated community care (ICC), its potential to have a transformative impact on population health and wellbeing, and how to successfully design and implement it.

The summarized findings from a diverse group of small-scale projects, to be published as a resource book on ICC in 2020\(^1\), demonstrate that the following principles are key to successful implementation and outcomes of ICC:

- Strengthening communities and targeting the social determinants of ill-health by reducing social exclusion and social isolation;
- Improving individual and community wellbeing;
- Building sustainable collaborative partnerships within communities such as between the health and social care sector, primary care professionals and neighbourhood actors to address public health problems;
- Encouraging people’s health seeking behaviours.

Lessons learned show that ICC requires a paradigm shift:

- at the citizen (micro) level, people engagement is fundamental for guiding community development. This means people are no longer only at the centre of care; their knowledge is considered as vital and no decisions concerning their life are made without their opinion. Instead of focusing on treating symptoms and diseases, goal-oriented care begins the conversation with what people’s life goals are and an assets-based approach to care starts with what people can do to achieve these.

  From the provider perspective, standards and procedures must be adapted and new connections made so that lived experience is recognized as expert knowledge and providers have access to a wider set of community resources oriented towards improving people’s wellbeing.

- at the community (meso) level, bottom-up initiatives and co-production ensure that services meet the needs of citizens and communities. Collaborative place-based approaches are at the centre of ICC. The establishment of new connections and networks among people and organisations are needed to enable place-based solutions. Creating a web of interdependent relations has the potential to strengthen social cohesion, reduce stigmatisation and build the structural integration required. Building resilient local communities inhabiting engaged people implies continuously asking what kind of life people want to live and collectively reflect on what is required to achieve it. Local governance helps to build trust and a sense that people can influence change. It means investing in collective decision-making to generate integrated primary care, embracing public health, social services and healthcare.

- at the system (macro) level, ICC calls for distributed power; from power held by a few, to power held by all. Decentralised power means change must be informed by everyone and we are all mutually held accountable. Being in a position of power today means you need to listen, learn to adapt and recognize that the process is what matters, and no system can be standardized. Different communities mean different needs, and to satisfy those needs, the only way is to shift to co-design and co-production. Enforcing standardisation hinders realisation of potential population-based models of care. As levers of policies, leaders must accept complexity and variability in the pursuit of high-level goals.

\(^1\) Will be available on the TransForm website in Spring 2020
Figure 1. Summary of the micro, meso and macro level characteristics of people-driven ICC.

Micro level
People-driven ICC is co-created among a team of professionals, family members, peers and the individual with a care and support need. Decisions are founded on individual assets, lived experience, life goals and professional expert knowledge.

Meso level
In ICC, collaboration is multidirectional and interdependent and involves wide social participation of everyone concerned. Building stronger local communities requires place-based governance for comprehensive solutions.

Macro level
At the system level, the barriers hindering equal access to health and well-being for all are targeted. There exists a shared vision for transformation and how to improve outcomes that matters to people. National, regional and local policies allow for distributed power, place-based and flexible solutions and collective learning.

More information from previous conferences is found here: Transnational Forum on Integrated Community Care.

2. The third TransForm conference in Vancouver

2.1 Main objectives of the conference

Communities can influence our health and wellbeing in many ways, including:

- **Social networks** and relationships reduce isolation and improve people’s resilience
- **Social cohesion** gives people a sense of belonging & of equality
- **Civic engagement** or participation gives people a sense of purpose and identity
- **Place based governance** for comprehensive solutions.
- **Local governance** helps to build trust and a sense that people can influence change

Figure 1 Based on a combination of the Glasgow Centre for Population Health Report on Social Contexts and Health and the Marmot Review (1).

The capacity of local communities to deal with complex public health issues and care needs of community members over their life course depends on the extent to which local, national and international actors are willing to foster community building and place-based initiatives. ICC also necessitates new cross-sectoral and interdisciplinary partnerships to be formed between all the relevant local stakeholders: citizens’ initiatives, voluntary networks, caring neighbourhoods, health and social care services, local associations, schools, third sector, social entrepreneurs and local authorities.

This conference will examine how to enable the participation and empowerment of communities in support of the objectives of ICC.

The conference main objectives are to:
1. Demonstrate through evidence and practical experiences the positive impact that community engagement and empowerment have at micro, meso and macro level on improving people’s health and wellbeing, including addressing social determinants of health.

2. Understand the options and processes by which local communities can participate meaningfully in local decision-making and governance processes to support integrated community care, including the creation and maintenance of new forms of partnerships and alliances, and the challenges and issues to developing a shared purpose.

3. Explore how to mobilise policy makers, community leaders and healthcare providers to take the lead towards system transformation through community-led, collaborative approaches;

4. Demonstrate how evaluation and research can support the design and deployment of community-based approaches that enable ICC.

5. Generate further inspiration and confidence to develop and change practice that values and encourages the role of the community at all levels: sectors, countries, communities, organisations and individuals.

2.2 The importance of community engagement and empowerment in improving people’s health and wellbeing

Involving local communities and citizens in the planning, design, governance and delivery of services using methods of consultation, collaboration, and/or community control has become a central strategy for promoting public health and developing sustainable primary care (2). It has been demonstrated that participatory approaches may be effective in improving health behaviour, health consequences, participant self-efficacy and perceived social support for disadvantaged groups (3). Giving a voice to the voiceless; children and young people, elderly, low-income groups and those marginalized is an important step towards more vibrant, resilient and inclusive communities.

Community engagement can take many forms, including volunteering, peer support, community coalitions, advocacy and social networks (4). Today, evidence on community engagement stems from collaborative interventions targeting healthy eating, physical activity, substance use, mental health, ethnic minorities and low-income populations (5). Here, community members are typically involved in varying degrees, including leading, collaborating, consulting or being informed about the design, delivery or evaluation of an intervention (3). Only when people are engaged and given a role from the very beginning, is it a good example of people-driven community development.

A successful example of how engaging people may strengthen communities’ ability to provide ICC is the example of Millom in South Cumbria, UK (see box). This case was presented during the TransForm conference in Hamburg.

**The Millom example**

In 2015, more than 2000 people walked the streets of Millom in protest against poor healthcare services and the closing of the local hospital. By inviting the citizens to public meetings and encouraging everyone to raise their voice and take part in the change required, local policy makers together with the residents of Millom, managed to turn the situation. Over nine months, multiple co-productive actions took place: a new town newspaper spreading health promotion messages, a new model of multidisciplinary primary care, opening of the first community paramedic, promotion of the pharmacy minor illness scheme, the general practitioner recruitment increased, and the community hospital reopened. ([Read more about the Millom example here](#)).
3. Core strategies to engage and empower communities

Interventions which empower communities cannot be standardised across different demographic areas or imposed from the outside. This is why strengthening communities’ abilities to design and commission socialisation of care, means decentralising and distributing power, resources and risks so that services are created within a local context and targeted to support specifically the local challenges related to citizen’s health and wellbeing (6, 7). Community-led development draws on the shared experience, interests, knowledge and needs of people, rather than being solely dependent on traditional provision of services (8). This asset-based and participative approach recognises that health equity and social cohesion stems from involving and making people co-owner for creating a community that supports their own and others wellbeing (2). It also acknowledges that individual action occurs within, and is maintained by a social context. Hence, interventions in the community setting should account for the social norms, attitudes and patterns of behaviour that reinforce unhealthy lifestyles.

Success in community and citizen engagement is linked to the extent to which people perceive real opportunities for being involved in local decision making on health and care issues, having their work appreciated and the cooperation with those locally in positions of power and influence.

One example is the concept of dementia-friendly communities, promoted by the Network of European Foundations through their European Foundations’ Initiative on Dementia (9). The ambition of this initiative is to improve the daily life of people with dementia by enabling dementia-friendly and inclusive environments in communities across Europe. The same principles lie at the basis of kinder communities and the power of everyday relationships, as showcased by the Carnegie UK Trust during the TransForm conference in Turin, 2019 (10).

3.1 Community-led development

The role of communities in improving people’s everyday life is receiving increasing attention in health policy and practice. Abundant communities, Asset-based Community Development (11, 12), Caring Neighbourhoods, Kinder communities and Compassionate Communities (10) are all examples of initiatives concerned about improving health and care, climate, local economy, children and youth upbringing and the life of those on the margins. These community-led innovations arise from local actors eager to take part in pragmatic experiments and to learn by doing. They challenge government policies and social services to explore new paths across sectoral boundaries.

Community-led development results from local concentrations of assets and energy for change offering tangible opportunities for improvement. It seeks to change situations of disadvantage and marginalization by including those who are affected by social injustice and bringing their collective experience to bear in defining the issues they face, recognizing what needs to change and identifying solutions. However, even when people are motivated to participate, they might experience barriers to communicating their preferences, needs, and values to others. Some of these barriers lie in the location of power in engagement processes, or they relate to language difficulties. Meaningful engagement of diverse populations therefore begins by specifically addressing the legitimization of their participation in informing healthcare decisions. Next, building a foundation of trust through which participants feel safe and comfortable is important, particularly in projects focused on sensitive issues, such as mental and sexual health (13). Strategies that have been suggested to enhance trust is to limit the presence and contribution of professionals and traditional decision makers, normalising people’s life-context by gathering people who have similar background and experiences and valuing life experience as evidence good enough to make decisions.

Communities as catalysts for change

As Jan De Maeseneer has stated: “A strong receptive low-threshold primary care enhances the sense of belonging and connectedness, because people who feel ‘taken into account’ are more willing to act, leading to more resilient communities” (14).
Integrated community care recognizes communities as actors for change, and not only as a setting for health and social services. It is also different from the participation of communities in pre-determined health initiatives, where participation acts as a mechanism to achieve programme outcomes (15). Building communities that bring residents together and provide a sense of belonging and connection leads people to be more willing to act for the common good. This is important, as over the past three decades, there has been a shift in how we connect with one another. Today, people report fewer social connections, a decrease in tolerance and trust and eroding political and civic engagement (16). However, the extent of people’s participation in their communities and the added control over their lives that this brings, has the potential to reduce isolation, improve health outcomes and mental well-being (17).

**Building resilient and inclusive communities through social capital, social cohesion and social inclusion**

In psychology, resilience typically describes the capacity of individuals to continue functioning in the face of adversity (18). While there are numerous individual protective factors contributing to resilience, a positive overall social context has been repeatedly emphasized, allowing the scope of the concept to expand to encompass entire communities and populations.

**Social capital** describes the links that bind and connect people within and between communities. It is formed by the capacity and will of members of communities to contribute to one another’s wellbeing. Physical closeness does not mean social closeness. A community with strong social capital is characterised by active and reciprocal voluntary effort, a strong infrastructure of diverse community groups and organisations and a significant level of influence in relation to wider decision-making processes that impact the quality of community life (19, 20).

**Social cohesion** refers to the shared values of communities that enable them to operate in an integrated manner, whilst respecting and celebrating difference. Cohesiveness is built on trust, hope, mutual respect and reciprocity. It provides people with a sense of belonging and equality, which is essential for everyone’s wellbeing.

One example, previously showcased through TransForm fostering social cohesion, is the community of Mirafiori Sud. This area has a particularly high rate of socioeconomically deprived elderly. To fight isolation and loneliness, different activities have been developed through active participation of the inhabitants targeted at place-based needs. Many of the activities emanate from Casa nel Parco, which is a neighbourhood centre open for everyone. Here, people with all kinds of backgrounds and capabilities can meet, cook and eat together, as well as participate in different educational courses and cultural activities. In this project, collaboration between the local health authorities, private foundations and a wider network of partners representing private, public and NGOs have successfully created a space promoting personal autonomy, independent living and improved quality of life for the population in Mirafiori Sud (Read more about Mirafiori Sud here).

In Canada, there are many examples of initiatives taken to meet the complex needs of rural and urban communities. One of them is the new St. Paul’s hospital, presented by Fiona Dalton.

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**Keynote Conference Abstract: Fiona Dalton, President and CEO of Providence Health**

**Relationship-based Health Care**

The new St. Paul’s is a catalyst for the transformation of health care in BC. The vision for the new St. Paul’s – the largest health care project in Western Canada’s history – is wraparound, personalized care for the patient – at the right time, and in the right place. This vision is informed by 125 years of compassion, collaboration, social justice, and innovation.

St. Paul’s provides patient- and family-centred health care to British Columbians. Our hospital is unique in that we’re located in Vancouver’s downtown core, and provide care for our inner city’s
most vulnerable, while also providing specialized care for patients with complex, chronic health conditions across the province – a place that’s larger than the UK and Ireland combined.

This keynote will address the challenges of providing community care across sizeable geography, and highlight St. Paul’s innovations to date in our efforts to provide patients with equitable access to care – whether they’re based in a remote community, or a member of a historically marginalized population in downtown Vancouver.

St. Paul’s has always been reliant on our relationships and partnerships to deliver on our vision: driven by compassion and social justice, we are at the forefront of exceptional care and innovation. We’ll explore St. Paul’s role as an enabler, creating knowledge and disseminating it quickly through collaboration across practice areas, and in partnership with provincial health authorities, providing specialist counsel to general practitioners across BC, in a bid to tackle some of BC’s greatest health threats.

We will share our vision for the new St. Paul’s, and its promise to put People First.

3.2 Community mental health services for young people – the Foundry approach

Teenagers and young adults experience the highest incidence of mental disorders of any age group in Canada. In 2011, nearly one in four young people aged 9-19 were living with a mental illness in Canada, yet, less than 20 percent received appropriate treatment. The second leading cause of death for young people is suicide.

We have decided to showcase Foundry in our third conference because it is one of the most successful examples of taking a completely different approach to helping young people before and after crisis. Foundry is a province wide initiative supported by the Government of British Columbia and several private foundations.

Foundry centres target young people aged 12-24 and provide a one-stop-shop for integrated mental health care, substance use services, primary care, social services and youth and family peer support. The transition from adolescence to adulthood is a major developmental challenge and a vulnerable period for the development and chronification of mental disorders. The traditional psychiatric help system is faced with the challenge of organising this transition in an optimal manner and supporting the adolescents in solving related problems.

By bringing health care and social services under one roof and focusing on wellness, empowering young people to live a balanced and fulfilling life, Foundry make it easier for young people to find help and support in this particularly vulnerable transition period.

Delegates are invited to choose between two different Foundry sites to visit: Foundry North Shore and Foundry Vancouver – Granville.

Keynote Conference Abstract – Steve Mathias, Executive Director, Foundry

How partnerships with community organisations can lead to true system transformation (lessons learnt from Foundry experience)

Foundry is an effort by young British Columbians and their identified family members, their communities, the Government of British Columbia, philanthropists, primary care, mental health, addiction, peer support and social service providers, and community non-profit organizations to provide a robust, sustainable and scalable network of care. Foundry has seen well over 140 organizations come together to intentionally co-create a system of care with young people and their families. Driven by provincially generated principles and rooted in a decade of health policy, Foundry began as a “Collective Impact” initiative in 2015, growing into a network of health and social service centres providing consistent and predictable services, and enhanced by online resources for young
Tackling health inequalities

Health inequalities is a consequence of systematic unequal distribution of power and resources among groups in society (24). Essentially this means that certain individuals or groups do not have adequate access to the social and material resources needed for health (protective factors), are more exposed and vulnerable to factors that are detrimental to health (risk factors) and more vulnerable to the social and economic consequences of ill health.

Unequal distribution of benefits is a concern that affects us all. Reflecting this, almost 200 nations have committed to the United Nations sustainable development goals (SDGs), based on the principle of advancing equity and leaving no one behind in the process of economic, social and environmental development (25). The likelihood of meeting SDG number 3 on good health and well-being is closely linked to the targets of goal number 11 on sustainable cities and communities. The Marmot review advises that meeting the health needs of disadvantaged populations and tackling inequalities in health requires addressing the level of control and influence that disadvantaged communities have over the factors that impact citizens’ health and wellbeing (1). Important elements in this sense is to reduce the access barriers for and increase vulnerable individuals’ capability to participate in civic life (26).

A video of Sir Michael Marmot presenting at the International Conference on Integrated Care 2019 is a useful source to gain deeper insight into research on health inequities and social determinants of health.

Determinants of health and well-being depend on a complex balance of social, cultural, political, economic and environmental factors, such as housing, employment, education, community networks and access to essential services (24, 27). These non-medical factors are responsible for up to 90% of health outcomes (28). Low socioeconomic status communities also appear to have lower social cohesion (29), which increases their vulnerability towards neighbourhood deprivation and inequity in health (30). Poverty and unemployment are significantly associated with reduced wellbeing (31), lifestyle problems (smoking, lack of exercise) and longer duration of episodes of common mental disorders such as anxiety and depression compared to people living in more affluent neighbourhoods (32).

In Vancouver, delegates will experience multiple successful examples of place-based interventions that help to address the social determinants of health. E.g. the Southcentral Foundation’s Nuka System of Care (Nuka) from Anchorage, Alaska, which is recognized as one of the world’s leading examples of healthcare redesign. The Nuka system has invested in establishing a range of primary care centres offering an inter-disciplinary set of services including primary care, dentistry, optometry, physical therapy, behavioural health, traditional healing and complementary medicine, outpatient services and residential treatment for adolescents and women. It is a whole health care system created, managed and owned by Alaska Native people that enhances culture and help empower individuals and families to take charge of their lives in achieving physical, mental, emotional and spiritual wellness.
3.4 Strengthening cultural competence

“We can never become truly competent in another’s culture but we can demonstrate a lifelong commitment to self-evaluation and self-critique” Minkler, 2005 (33).

Ethnically, culturally and linguistically diverse communities often experience difficulties in accessing appropriate health services because of physical, cultural, psychological or financial reasons (34, 35). Also, culturally diverse patients are often disadvantaged in mainstream systems because they are unable or unlikely to advocate for their own welfare in healthcare. Although the benefits of cultural competence (i.e. the ability to build relations to people and understand their day-to-day experience with unique place-based constraints) are clear from a clinical standpoint, the complexity of conceptualising and applying cultural competence to health and social care remains a major challenge. Culturally adapted interventions are grounded in the lived experience of people with diverse values, beliefs or behaviours (36, 37). So far, standardised frameworks, measures, benchmarks and evidence of longitudinal outcomes of cultural competence interventions are lacking, leaving the obligation of culture responsiveness left to service providers (38).

Culture is not a concrete, objective phenomenon, but something that is fluid, constantly reshaped, collectively imagined, socially constructed and renegotiated. Important also, is that determinants of wellbeing may vary across cultures (39). As a place to start, culturally sensitive adaption processes involve (40):

1. Gathering stories of the obstacles and barriers people encounter;
2. Identifying mismatches between the original intervention and people’s daily lived experience, culture and values; and
3. Evaluating changes that have been made to rectify these disparities

Next is to use these learnings in education of professionals and organisations to avoid generalization and stereotyping that may undermine the patient-provider relationship and exacerbate poor health outcomes among minority populations (41). A recent systematic review showed that cultural competence training interventions could significantly increase the cultural competence level of healthcare providers and that such training was significantly associated with increased patient satisfaction (42). In addition to focusing on appropriate and effective communication skills, the use of interpreters and the involvement of community health workers, it is suggested that a cultural competency training program covers the following culturally related topics (43):

- Differences in perceptions and beliefs about causes of illness
- Attitudes toward treatment and medication adherence
- Health belief theories
- Family structure and roles
- Importance of religion
- Self-medication, traditional and/or herbal remedies and healers
- Acceptance of Western medicine
- Lack of preventive care
- Common Dietary practices
- Stigma of mental illness

Culturally competent health care is not yet a norm in health services and there is an urgent need to invest in the development of culturally competent health and social services (44). The Immigrant Services Society of British Columbia (ISSofBC) is one of the largest immigrant-serving agencies in Canada, with a national and international reputation in the field of migrant issues and services for immigrants and refugees. During the conference, delegates will experience how the ISSofBC team promotes acceptance and mutual respect and helps build immigrants’ futures at the same time also building a
stronger future for Canada. This is only possible by believing that everyone’s path to integration and self-sufficiency is based on a recognition and acceptance of that person’s unique needs and aspirations.

Another organisation, also catering culturally sensitive services, is Vancouver Native Health Society (VNHS). VNHS deliver comprehensive medical and social services to the Indigenous community of Greater Vancouver. Particularly, their services are founded on traditional Indigenous knowledge and methodologies, which aim to promote the mental, emotional, spiritual and physical health of Vancouver’s urban Indigenous people.

3.5 Place-based governance for context sensitive and comprehensive solutions

Improving care integration with a focus on community is complex and highly context- and value-dependant. It relies on possibilities to involve stakeholders at a decentralised level in decision making and collective actions. A participative approach in both decisions and actions also implies that adaptation through learning is necessary. This is at the centre of place-based governance. Indeed, in such an approach, the assumption is that decision and action is strengthened through gaining a progressive and locally shared understanding of the ‘life’ of a community. This mode of governance is often presented as an alternative to the still predominant New Public Management (NPM) model of governance. NPM focuses on centrally controlled and objectively measurable targets as a guaranty of accountability (see table below). This is now considered inadequate and unfit for a complex endeavour, such as ICC.

Table 1. Key differences between NPM and place-based governance (Inspired by Marsh I et al. 2017 (45))

<table>
<thead>
<tr>
<th>New public management</th>
<th>Place-based governance</th>
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<tbody>
<tr>
<td>- Centrally determined targets and metrics (objectively measurable)</td>
<td>- Local governance structure grouping stakeholders from different organisations for comprehensive solutions</td>
</tr>
<tr>
<td>- Performance based payment (P4P or P4Q)</td>
<td>- Uncertainty managed through trust-based relationships</td>
</tr>
<tr>
<td>- Often management per speciality or organisation</td>
<td>- General frameworks centrally defined</td>
</tr>
<tr>
<td>- Knowledge focused on «the one» intervention to «copy» everywhere</td>
<td>- Local adaptation – learning by doing</td>
</tr>
<tr>
<td>- Controlled test of intervention at the centre of learning process</td>
<td>- Whole system thinking at the centre of learning process</td>
</tr>
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</table>

Place-based governance is far from being the standard way of working. Transformations is needed both at the individual, local and larger (macro) level of the health and social care system.

At the individual level, this requires a change of mind-set, in such a way that policy makers and experts recognize that the knowledge of citizens and community-representatives is pivotal and that the mundane, lived experience of people and their needs, is what matters most(46) (49).

At local level, place-based governance involves changing routine and institutional arrangements to break silos and to make effective dialogue between social, health and local development agencies. This should be complemented with mechanisms facilitating participation from the users of community services so that strategies are co-constructed, shared and informed by their values, the particular circumstances and the social infrastructure (47).

At macro level, the policy makers and leaders are expected to radically change their relations with leaders at the local level. For example, leadership to foster place-based governance at local level relies on a composite set of capabilities and behaviours, such as (48):

- Identifying and scaling innovation; instead of piloting intervention, fund innovation programs
- Having a strong focus on population health and wellbeing
- Building strong relationships with different agencies at macro level, and often working with them informally to develop joint priorities and plans
- Understanding and leading cultural change
- Building system-wide learning and evaluation frameworks
- Particularly reflect on what counts as legitimate knowledge within organizational processes, who are the providers of this knowledge and how it is utilised
- Make explicit who is in control of what through negotiation across all levels of integration
- Fostering a learning culture across the whole system

This form of leadership is particularly challenging to implement at the macro level. Citizen participation is always just one policy imperative among many others. In a market-based system, professionals, managers and policy makers continuously need to weigh the relative importance of competing interests. With mutual responsibility for common values follows the handling of a multiplicity of accountabilities, a potential decrease in efficiency, turf protection and competition for resources. Also, specifically for public servants and bureaucrats, are their obligation in meeting the vertical accountabilities associated with ministerial priorities, which can strongly influence what is allowed and not allowed to happen (49).

### 3.6 Financial mechanisms to stimulate and sustain ICC innovations

Payment can provide a key incentive for multi-sectoral collaboration and in aligning care to whole system goals (50). In the previous TrasForm conferences, showcased examples of promising practices have typically been funded by a combination of public and private (NGOs, sponsors, innovation funds etc.) money or through fundraising, donation, volunteering and/or participant fees. In general, these examples are bottom-up initiatives, where a central challenge is to secure financial stability and predictability over time, as well as supporting flexibility, collaboration and innovation.

Integrated funds for health and social care are one of several approaches assumed in policy to improve health outcomes and lower costs for people with complex care requirements (51). Yet, the evidence for the latter argument is weak. Rather, one must be aware that total care costs are more likely to rise due to increased uncovering of unmet needs (51, 52). Resolving these needs can benefit both individuals and society. If integration delivers improvements in quality of life, even with additional costs, it may, nonetheless offer value for money. It is also possible that looking to outcomes, inter-sectoral and long-term, the overall result may be cost-effective. In Scotland, altered legislation and decentralisation of power to local Integration Authorities (IAs) has allowed for ‘integration joint boards’ working across health and social care. In total, IAs oversee spending in excess of £8 billion, which is most of all public care spending in Scotland. However, several IAs face financial pressures and Audit Scotland reported difficulties with short-term and late budget settlements of the IAs for 2018 (see the poster presentation of how Scotland develop policy across sectors here) (53).

Fee-for-service payment, Diagnosis Related Groups (DRGs) and fixed budgets are the most prominent payment models today. These models encourage high-intensity and procedure-based care. Moving towards a population-based patient management system implies new, inventive models to be developed and that reimbursements are tied to quality of care (54). Pursuing on a course of quality-related payment mechanisms will not only require extensive focus on quality data (including patient reported experiences and outcomes) but also on costs and cost drivers. To match up the national strategy with local delivery systems, one must recognize that services need to be developed within localities and that the ability to customize care for individuals is crucial.

Following are examples of payment models that, used in combinations according to needs and health system goals, could support ICC. However, further experience and research with the different models, and different models used in combination, is needed.
Pay for coordination (P4C)

In a P4C system, the provider or care team (including a case manager) get rewarded for coordinating activities like reviewing or documenting patient data or meeting with other providers (55). P4C should be combined with other incentives to reduce unnecessary health care expenditures and secure high-quality care.

Population-based payment frameworks

This is the broadest form of bundled payments, where a single payment covers all care provided to all patients living in an area over a defined period of time. Transfers would not be made to individual providers but to large-scale health care organizations organizing and paying individual providers for all care needed by the adherent populations.

Incentives specifically targeted at improving care quality

In the case with bundled payments/shared savings models and in the absence of adequate mechanisms to monitor and reward quality, one must be aware of the risk of providers attempting to cut costs by reducing the provision of services, disregarding patient needs and thereby, providing lower quality care. If quality can be reliably measured and if quality attainments can be attributed to the providers, it is possible to develop incentives that encourage providers to achieve better outcomes. This may involve contracts that bonus practices according to the proportion of staff having training or certification in culturally sensitive approaches, multimorbidity, geriatrics etc., or bonus (or penalty) schemes related to complication rates, avoidable hospital admissions, patient satisfaction or the proportion of patients treated according to guidelines (56). Designing adequate incentives for quality improvement is not straightforward and requires considerable concerns regarding which indicators to use and how, the definition of targets (e.g. absolute targets or relative targets), the level of the payment adjustment (e.g. individuals, groups, institutions) and the use of risk-adjustment. Committing payments to superior outcomes may foster innovation in workflow processes and improve understanding of what techniques lead to the best outcomes (57).

Community currencies

Abundant communities nurture a culture of giving and receiving. The need for more socially, economically and environmentally sustainable systems of finance and exchange has never been more evident than it is at present (58). Community currencies (CCs) systems have been proposed as an alternative way to foster local economic activity, social capital, cooperation, trust and cohesion (59). CCs can facilitate resource-sharing, new social institutions for collaborative consumption and a sense of purpose for socially-excluded groups. Implicit in this model is the view that everyone has something to offer, including those whose skills are not valued by the formal labour market (60).

For example, by putting a value on people volunteering their time and skills, currencies such as Spice Time Credits can bring communities together to meet local needs. Spice Time Credits is swapped for volunteer work in the community and can be spent on a range of community, cultural and leisure activities locally. They can also be spent across the national network of organisations that are currently participating in the programme.
4. The added value of developmental evaluation and research in ICC

Evaluation and research play a major role in ensuring that health and social care is sustainable, effective, efficient and safe. Traditionally, there has been a gap between what is known from research and the care that is provided in health systems, and this gap has been said to be caused by a knowledge transfer problem. However, emergent thinking rather considers knowledge production as contributing to the know-do gap if the users are not involved in defining what is knowledge generation (61).

Participatory models of evaluation and research

Developing models of ICC entails complex service innovation. There are no simple or direct ways to measure health and wellbeing or whole system change. Evaluating people-driven approaches require moving away from top down summative and formative evaluation processes towards a developmental and emancipatory learning process (62). To understand its complexity and how the different activities are connected and interplay, flexible and participatory approaches to evaluation and research are needed (63).

Participatory modes of research and evaluation emphasize the importance of creating partnerships with the people for whom the research is ultimately meant to benefit. Thus, the “gold standard” randomised controlled research design is not useful when knowledge are to be generated collaboratively from researcher and end user expertise. Very little can be said beforehand about where these processes will end and what results to expect. Integrated knowledge translation (IKT) is one of the proposed approaches to address the problematic issues inherent in traditional research methods and knowledge generation. IKT was initially advanced by the Canadian Health Services Research Foundation and Canadian Institute of Health Research (64). IKT draws on a complementary partnership where the users hold contextual information about the challenges to be solved, whereas the researchers or facilitators contribute with expertise in methods and methodology. Similar approaches are often referred to as community based participatory research (CBPR), mode 2 research, realistic evaluation (65) or theories of change (66).

Through community participation policy and practice, these methodologies aim at developing context-sensitive, applicable evidence through co-creation of knowledge. Thus, the results include outputs, outcomes and impacts, where impacts are the final outcomes affecting well-being. These results may take the form of proxy measures of prosperity or sets of questions that combine different characteristics of a phenomenon to provide some overall score or ranking.

Indirect assessment of community development may include complex values such as citizen power, number of residents participating and co-producing in civic life (particularly those who have been marginalized), exchanges of gifts/care/time and deepening of associational life (note the link to community currencies). It could also include assessing the degree of social cohesion, e.g. measured through social trust among citizens, rates of corruption or even right-wing voting. Additionally, these processes are set out to understand how the activities of the intervention are expected to lead to the desired results and under what conditions the various links in the causal pathway are expected to work. Important here are the changes in knowledge, attitudes, skills, aspirations and opportunities of those who have been involved.

Although IKT, theories of change and similar methodologies have a wide range of possible uses in developing, managing, and evaluating interventions, they are criticised in terms of practicality, usefulness and theoretical difficulties (67, 68). Also, these approaches typically have fewer funding opportunities available.
Developmental evaluation

Developmental evaluation (DE) is a relatively new approach to evaluation that supports the creation and implementation of dynamic, complex innovations. DE is used to define and refine new models and approaches at the earliest stages of innovation, when the path to achieving success is unknown and evidence regarding expected outcomes is scarce or unclear (69).

Developmental evaluation, pioneered by Michael Quinn Patton, has emerged as a way to support adaptive learning and creative thinking in initiatives involving high levels of uncertainty, innovation, emergence, and social complexity. Developmental evaluation processes include asking evaluative questions and gathering information to conceptualize, design and test new approaches in a long-term, on-going process of continuous improvement, adaptation, and intentional change. The evaluator’s primary function in the team is to elucidate team discussions with evaluative questions, data and logic, and to facilitate data-based assessments and decision-making in the unfolding and developmental processes of innovation. Hence, the purpose of DE is to provide real-time feedback and generate learnings, not judgment, to inform development. This is in contrast to how evaluation traditionally has been designed to provide cover for the granter in terms of value-for-money, rather than to provide useful information for the recipient.

DE is a context-specific approach - as such, there is no prescribed methodology. The “right” method is determined by need and context. However, developing a learning framework might be useful to set direction for learning and project development. A learning framework maps the key challenges and opportunities by identifying what the group needs to pay attention to as they go forward and what they need to learn.

DE is increasingly being applied in youth health and social care spaces in Canada. It is an effective approach to support innovators by identifying new ways to analyse and assess how well services work for young people. As can be read in the abstract below by Amy Salmon (who will lead a workshop on DE during the conference), typical questions to be answered during a DE process are “What do we have to learn to get where we want? What are we curious about? What is keeping us back?” (70).

Conference Abstract

Dr Amy Salmon – A workshop on developmental evaluation as a tool for systems transformation

This workshop will draw on examples from recently completed and in-progress DEs at Foundry to discuss the application of DE as a mode of inquiry to frame, clarify, and analyse “complexity concepts”, linear and non-linear relationships, and intended and unintended consequences of interventions in integrated care for youth. We will show how we have used DE to explore questions such as:

- What are core components that make up a Foundry centre?
- How do we decide what supports are most “necessary”, and for whom, in the context of an integrated service model?
- How do we define and act on key concepts such as “access”, “integration”, “low barrier”, and “empowerment”?

We will also describe how DE can create space in evaluation processes to centre the voices, experiences, and priorities of young people and families alongside those of service providers, decision-makers, and funders. Findings will be presented that address such questions as:
- What have we learned through DE about which outcomes are most meaningful to youth and families?
- What space can DE create for conversations that redefine what “success” and “effectiveness” look like from their perspective?
- What potential does DE have for building the evidence base needed to transform the delivery of integrated health services?

5. Why Canada?

Canada is often defined by its diversity. Home to millions of people from different backgrounds and cultures, more than 200 languages are spoken across the country, with 20 per cent of Canadians having a language other than English or French as their mother tongue (ref: Statistics Canada). The Graham Boeckh Foundation, the Conconi Foundation and the St. Paul’s Foundation, partners of the TransForm initiative, recognize Canada as an important country on the international stage to showcase innovative practices of integrated community care and community-based learning, both from a policy and practice sense (e.g., see the Kudoz partnership –see box).

Kudoz

Kudoz is a partnership powered by four organizations in BC (among them posAbilities) that came together in 2015 to improve the life of adults with cognitive disabilities.

“Frane shares botany. Cassandra shares stunt doubling”.

Kudoz enables people to flourish. Adults, and particularly persons with cognitive disabilities, can easily get stuck in a rut. A flourishing life needs meaning and purpose and Kudoz represents a catalogue of hundreds of different possibilities for learning, reflection and recognition. This initiative gives people the opportunity to shift course, to widen and deepen their interests and to find meaningful roles in their community.

Learning experiences

Typically, disability services work by asking individuals what they want to do without first creating a wide experiential base from which to choose. Kudoz’ approach is opposite and provides this experiential base. Their activities are framed by several theories, such as social cognitive career theory, social stigma theory, learned hopefulness theory and bridging social capital theory.

For any of us to find a good job, we first need to have articulated interests. And to have interests, we need great learning experiences. Learned hopefulness is the process of learning and utilizing problem-solving skills that help us feel more in control. Kudoz is all about reinforcing these skills and to ‘bridge’ people to fresh opportunities. These connections allow different groups to share and exchange information, ideas and innovation and increases our ‘radius of trust’ (in contrast to ‘bonding’ approaches, which refers to the kinds of opportunities that link people to others with similar interests and skills).

See also: http://kudoz.ca/

Canada has experience with culturally sensitive approaches with regards to empowering indigenous communities and marginalized communities (see section 5.1). The country has a strong track record on involving youth in community initiatives, an area that is garnering increasing interest globally. The
Foundry organization is particularly showcased due to its successful work with preventing and handling mental health in young people (read more about Foundry and their work in section 5.2).

Canada has a publicly-funded health care system which is defined and regulated by the 1984 Canada Health Act. This law allocates supervisory and financial functions to the federal government and responsibility for management and delivery to the provincial governments.

**Indigenous populations**

Indigenous populations are unique cultural and ethnical groups the original settlers of a given region, in contrast to groups that have settled or occupied the area more recently. Today, there are about 370 million indigenous people living in more than 90 countries worldwide (71). However, their ability to influence and participate in the external policies that may exercise jurisdiction over their traditional lands and practices is very frequently limited (72). Several of the challenges Indigenous peoples confront are related to cultural and linguistic preservation, land rights, ownership and exploitation of natural resources, political determination and autonomy, environmental degradation and incursion, poverty, health and discrimination (73). The UN Declaration on the Rights of Indigenous Peoples (ref 6):

"emphasizes the rights of Indigenous peoples to maintain and strengthen their own institutions, cultures and traditions, and to pursue their development in keeping with their own needs and aspirations".

It also:

"promotes their full and effective participation in all matters that concern them and their right to remain distinct and to pursue their own visions of economic and social development".

In Europe, indigenous populations are relatively few, mainly confined to the northern and far east part of the continent. Contrarily, indigenous peoples reside in all nations in North and South America.

**Indigenous populations in Canada**

The indigenous peoples of what is now known as Canada consist of three groups: First Nations, Inuit and Métis, although within these broad categories there is tremendous diversity in terms of languages, cultures, history, way of life and Nations (74). They have a rich history of wellness that extends back in time for many thousands of years. First Nations and Inuit governments, families and individuals practiced active territorial stewardship, contributed to strong and thriving economic systems, and enjoyed good health and wellness due to a lifestyle that was active, based on healthy traditional diets and enriched by ceremonial, spiritual, emotional and healing practices. Complex social and cultural institutions existed within these Nations, which oversaw the careful management of resources to ensure sustainability and long-lasting abundance (75).

The arrival of European settlers and subsequent imposition of colonialism marked a change of course in the wellness journey of First Nations, Inuit and Metis peoples. Settlers implemented aggressive tactics and policy initiatives as part of an oppressive colonial agenda designed to eliminate self-determination and jurisdiction and disempower and degrade First Nations, Inuit and Metis health and wellness, practices, beliefs, and values, creating a legacy of trauma and health and social inequities. Today, First Nations, Inuit and Metis continue to be impacted by the legacy of colonialism, including experiencing stigma, racism and discrimination in their interactions with society (75).

Despite continuing to be impacted by colonialism and oppression, First Nations, Inuit and Metis are resilient and continue to thrive and reclaim self-determination. This includes continued work to shift the paradigm and social narrative to one that is strengths-based and includes a wellness focus; to support social processes to examine and dismantle colonial structures and implicit and explicit bias and racism; and to work with federal and provincial governments to support implementation of the United Nations Declaration on the Rights of Indigenous Peoples (76) and the Truth and Reconciliation Commission of Canada: Calls to Action (77). This call for action is a response to how children, forcibly if
necessary, have been taken from their families and placed for much of their childhoods in residential schools to minimize and weaken family ties and cultural linkages, and to indoctrinate the children into the culture of the Euro-Christian Canadian society. This practice has existed for well over 100 years and is referred to as a "cultural genocide" of Indigenous Peoples (78).

According to Statistics Canada, in 2016, there were 1,673,785 Indigenous people (First Nations, Métis, and Inuit) living in Canada (79). Among these, 270,585 resided in BC (80), which is an increase of 38.5 per cent since 2005 (79). Among BC’s Indigenous population in 2016, 63.8 per cent (172,520) were First Nations people, 33.0 per cent (89,405) were Métis, and 0.6 per cent (1,615) were Inuit (81). However, at this time, data captures an incomplete picture of the Indigenous population of BC based on the legal distinctions of who meets the criteria for registration and those who have chosen not to be registered. For example, a person who identifies as First Nations but is not registered and therefore a Status First Nation is not captured in health administrative data sets. As a result, the data mentioned above should be interpreted with caution.

First Nations in the Province of British Columbia

First Nations in BC continue to demonstrate self-determination, leadership and resiliency in their health and wellness journeys. Many partnerships have been created and strengthened with a shared vision of supporting the health and wellness of First Nations through the exercise of shared decision-making. The Tripartite health partnership between the Province of British Columbia, BC First Nations and the Government of Canada that has been evolving since 2005 is the first of its kind in Canada and in many ways, worldwide (see text box below).

Through this health partnership, First Nations and federal and provincial governments are supporting First Nations to exercise self-determination in the design, delivery, and decision-making related to health and wellness programs, services, and systems. Through this process, systemic racism and bias is being tackled, relationships are being improved, the health system is embedding First Nations definitions of health and wellness, and there have been positive shifts in health outcomes such as infant mortality and youth suicide (although work continues to address a range of disparities in health outcomes such as suicide (82), poverty, unemployment, food insecurity, homelessness and housing insecurity (83).

The First Nations Health Authority (FNHA)

FNHA is the first province-wide health authority of its kind in Canada. FNHA serves as a health and wellness partner to BC First Nations children, families, and communities. The organization works with communities, health service organizations and health system partners in BC to blend the “best of both worlds” to support First Nations access to high quality, culturally safe health and social services with the goal of improved health and wellness outcomes. FNHA undertakes strategy and policy development, strategic planning, and population health data and research to inform the design of health and wellness services and systems. FNHA also operates as a direct funder and deliverer of care, including in mental health and wellness, environmental public health, nursing and oral health, among others. FNHA provides training, tools and resources to support First Nations communities in health planning and administration. The illustration below captures FNHA’s philosophy:
In December 2014, the FNHA created the Office of the Chief Medical Officer (CMO), led by Dr. Evan Adams. The CMO’s role is to provide health and wellness leadership, and to honour and promote both traditional Indigenous and Western approaches to health, wellness, medicines, and healing.

We are pleased to announce that Dr. Adams will take part in the TransForm Conference in Vancouver.
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