



Engaging people with lived experience and community participation as the basis for Integrated Community Care

TransForm changemakers' experiences and joint reflections

TransForm Integrated
Community
Care



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Glossary

Community: a social group whose members have something in common, such as a shared geographic location, culture, or heritage. For most change-makers, the concept of community is not separate from professionals and institutions, however for some it can refer to grassroots movements. In its more comprehensive definition, the term encompasses all actors that are relevant for the common good of health for all in a defined geographical area.

Community worker: is an umbrella term that includes all potential different roles used in various countries such as animatore, educatore, 'neighbourhood flatterer'. This can be a person with lived experience or a professional. The shared characteristic is that it is someone who is willing to listen, build connections and co-create wellbeing with all stakeholders in the neighbourhood.

Co-creation: the active process of engaging diverse stakeholders to understand and solve problems with the aim of designing, implementing and evaluating relevant solutions together.

Community participation: A process through which community individuals, groups or organizations plan, carry out and evaluate activities on a participatory and sustained basis to improve their health and other needs, either on their own initiative or through the health advocacy of others.

Empowerment: a process through which people gain greater control over decisions and actions affecting their health, wellbeing and quality of life. It can also be defined as perceived control over the social, economic, and political aspects of one's life.

Lived experience: the things that someone has experienced themselves, especially when these give the individual a knowledge or understanding that people who have only heard or learned about such experiences do not have. Related terms include experts by experience, lived expertise, living experience, patient expert. In this document, the term encompasses two dimensions: a) experts about their own life and b) experts as peers (supporting others)

Meaningful engagement: respectful, dignified and equitable process of integrating individuals with lived experience across a range of processes and activities, transferring power to people, valuing lived experience as a form of expertise and applying this to improve health outcomes and quality of life.

Participatory approaches: conceptualized as a continuum in research where different levels of participation imply different amounts of community control over the process and outcomes. For changemakers it tends to mean that community members are empowered as equal partners to define and execute the research as well as to determine its applications.

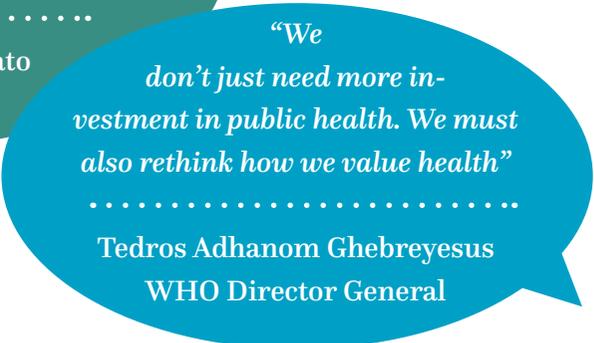
Introduction

As we face crises after crises (climate, geopolitical, health, financial), each one increasing inequalities and impacting most on people in vulnerable situations and on marginalised communities, we need to come up with new and better ways of living and caring for people and the planet. Most challenges we face today are complex and interrelated and to solve them requires participation from communities and citizens, working together with the state and the private sector towards the common good.



“Care is the life-giving force that sustains health and well-being, binding together societies and ecologies. But everyday forms of care, though essential, are systematically undervalued”

.....
Mariana Mazzucato
Economist



“We don’t just need more investment in public health. We must also rethink how we value health”

.....
Tedros Adhanom Ghebreyesus
WHO Director General

As part of this, the mere concept of care needs to be redefined beyond ‘hands-on care’ that is offered in response to needs (the ‘caring for’) to a social capacity and activity involving the nurturing of all that is necessary for the welfare and flourishing of life (‘caring for, about and with’)¹. The current system of care was designed in and for the industrial era – an era of hierarchies and production lines, where most diseases were either curable or led to early deaths – and it has reached the limits of what it can achieve. Ironically, the current healthcare system which focuses on the purported ‘best’ use of limited resources, has constrained our ability to care. Today’s diseases are chronic and complex and require different responses. We need to reimagine and create a system designed for the problems we face today². To care not only cure. In other words, to care as the cure for our modern-day malaises.

Integrated Community Care (ICC) has evolved and is based on a range of important innovations and efforts in the field, such as people centred care, community primary care, integrated care, social determinants of health, goal-oriented care, amongst others. ICC acknowledges that each of these, although important, are not enough on their own and brings them together. ICC takes a person’s and community’s strengths, goals and needs as a start point and focuses on tackling inequities in health. It is not a prescriptive approach, or a managerial toolbox, but rather a set of principles ([see Box p. 9](#)) that guide a range of existing practices that are changing the way health and care are organised, towards people-driven care³.

ICC is very much aligned with the World Health Organisation (WHO) vision for primary health care, as well as with the latest developments from the WHO Council on the Economics of Health for All⁴ which outlines three key objectives - from the planetary to the individual scale:

- 1 **valuing planetary health**, including essential common goods such as clean water, clean air and a stable climate, with respect to planetary and local ecological boundaries;
- 2 **valuing the diverse social foundations** and activities that promote equity, including social cohesion, supporting people in need and enabling communities to thrive, and;
- 3 **valuing human health and well-being**, with every person able to prosper physically, mentally and emotionally, and endowed with the capabilities and freedom needed to lead lives of dignity, opportunity and community.

Major influences on ICC include Jan de Maeseneer's⁵ extensive work on community-oriented primary care, as well as Michael Marmot's work on the social determinants of health⁶, John McKnight's⁷ and Cormac Russell's work on asset-based care⁸. Mariana Mazzucato, Chair of the WHO Council on the Economics of Health for All and Hilary Cottam, author of Radical Help^{9,2} have also been sources of inspiration in their call for a rethinking of the role of government – emphasizing that contrary to what may be popular belief, it is often thanks to the state and public funds that important innovations, such as the National Health Service and the moon landing, have come to fruition. To be innovative, requires us to be collaborative, ensuring that society, the government and corporations share a common goal, not only taking risks together but also sharing the rewards.



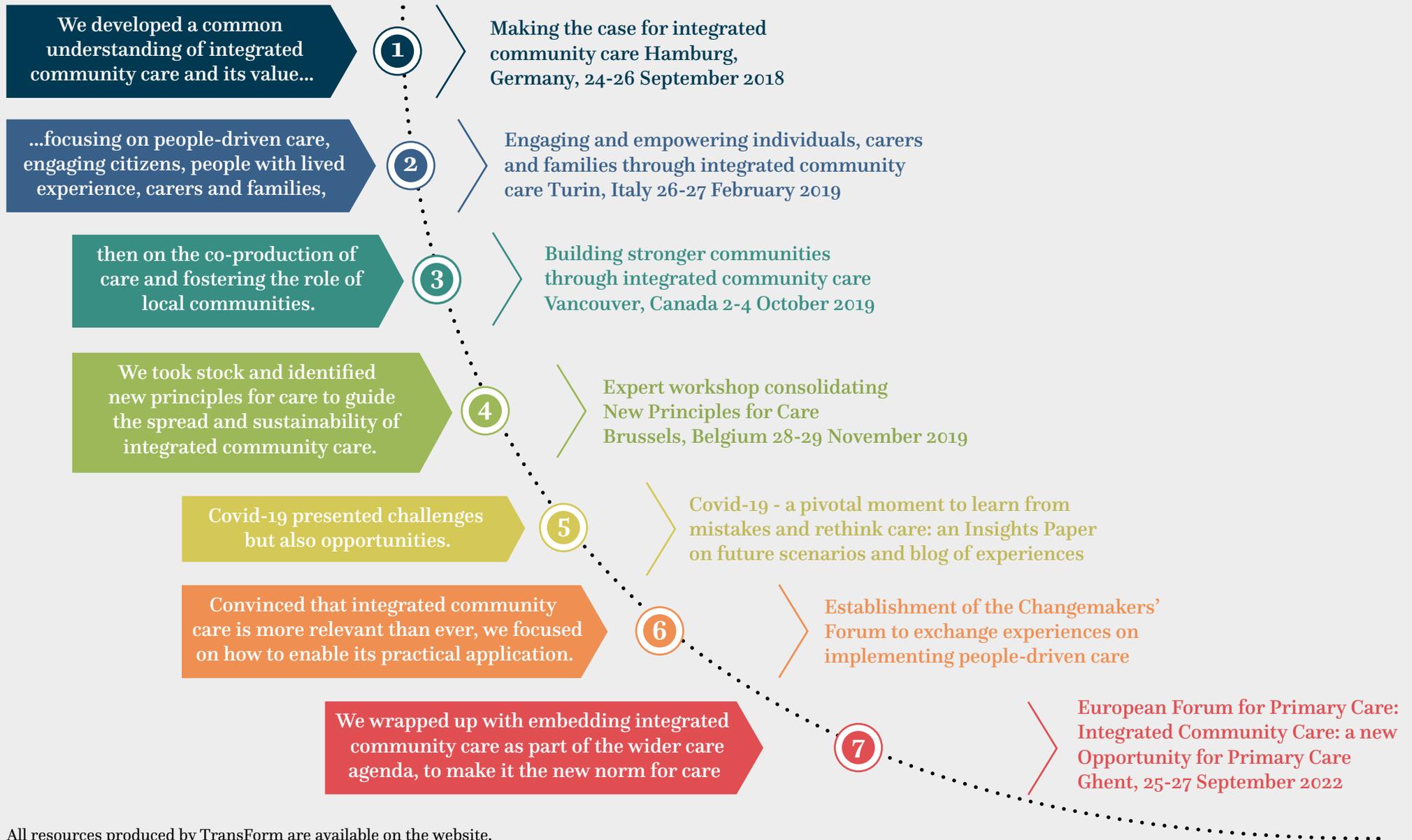
What is TransForm and who are the Changemakers?

The Transnational Forum on Integrated Community Care (TransForm) is a learning coalition of philanthropic foundations in Europe and Canada that came together in 2018 with the aim to put the community at the centre of primary care and integrated care. Through a series of research activities, including a mapping of existing ICC practices in Europe and Canada, international conferences that included several site visits, and workshops, TransForm has identified, together with academics, decision-makers, practitioners, people with lived experience, and citizens the foundations of ICC - its key values, principles, ingredients, challenges and facilitators. For more information on the concept of ICC see Integrated Community Care 4all. Seven Principles for Care. Strategy Paper to move ICC Forward^{10, 11}.

TRANSFORM'S JOURNEY...

THE STORY

THE ACTIVITIES



Seven effectiveness principles for Integrated Community Care

How to turn Integrated Community Care from aspiration into reality? Rather than to focus on elaborate strategies we propose a limited set of effectiveness principles to guide action in a complex transition.

An effectiveness principle is a clear and actionable statement that provides guidance for thinking and behaving toward some desired result. It informs choices at forks in the road, grounded in values about what matters to those who develop, adopt, and attempt to follow them.

As a set, they provide an overarching agenda for collective impact. The seven effectiveness principles are:

CO-DEVELOP HEALTH AND WELLBEING, ENABLE PARTICIPATION

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

BUILD RESILIENT COMMUNITIES

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

MONITOR, EVALUATE AND ADAPT

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

A crucial part of this learning journey has been the contribution of ICC changemakers.

In 2021, an independent selection committee comprised of experts and advocates within the field of integrated community care selected a range of promising, innovative initiatives to join the TransForm's Changemakers Forum. Their goal was to exchange knowledge and identify priorities to advance the field of integrated community care. The consensus they reached was that the start point to ICC should always be the meaningful engagement and participation of people – individuals with lived experience and communities.

The TransForm changemakers are all different - they reflect a wide range of practices and different stages of development – but they all embody most ICC principles. They are redefining care for the modern world and as such provide us with real examples of what the future of care could look like.



The changemakers included in this document are described in alphabetical order in the list below. There are several more that were part of the TransForm journey that have not been included here but whose descriptions you can find on the TransForm website

TransForm Changemakers' Workshop at the European Forum for Primary Care in Ghent 2022



#Com.viso^a

community development and a wide range of support to people in vulnerable situations in remote areas in Monviso, Italy.



aMi città¹

Community Personal Health Budget – support for adults with long term mental health conditions in Milano, Italy.

CALICO (Care and Living in Community)



a partnership that shares the collective goal of building a healthier form of housing and living, as a community in Brussels, Belgium. It provides affordable housing and teams up with the University Hospital to provide maternity and palliative care in a home environment.



Caring Communities^b

partnering with patients and citizens working as peers and full members of integrated community care teams. Peers mobilize their lived experience and skills to bridge community and professional care for people with complex medical and social needs, based on their own life goals. Based in Montreal, Canada, this is a generic community-focused intervention rather than a disease or age-specific initiative.



Centro Paideia

a project started by Paideia, a Family Foundation based in Turin and Milan working to improve the lives wellbeing of children with disabilities and their families and promote an inclusive culture involving the community.



Eerstelijnszone Regio Aalst (ELZ)

one of the 60 primary care zones that were commissioned by the Flemish government in 2020, seeking to bring health care, civil society organisations, welfare, local governments and citizens together to implement integrated and goal-oriented care.



Foundry^c

transforming health and social services for young people, in Vancouver, Canada and beyond, by bringing partners together in a single place and integrating services. The focus is on early intervention and providing mental health, substance use services, peer support, primary care and social services, as well as navigation to specialized services, creating seamless pathways of care.

a) #Com.viso and aMi città have come to an end as projects but the ways of working they pioneered described in this document have been embedded and continue being championed by the partner organizations. The aMi città approach is now implemented through a new project called R2 - Recovery In Rete, led by the Solidarietà in Rete Consortium in partnership with Lotta Contro l'Emarginazione and more than 23 nonprofit organizations, including family and user associations and local Mental Health Departments. This new project received a financial support from the Municipality of Milan and is currently implementing 60 community health budget projects.

b) Other related sites: La Salute in testa / RUL Rete Utenti / Lotta Contro l'Emarginazione

c) Foundry and Caring Communities were part of earlier TransForm case studies and are changemakers in their own right. We have included them here to share some experiences in Canada as well as in Europe.



GEKO

(Gesundheitskollektiv)

a community health centre focusing on the neighbourhood and working together with the residents to improve health and promote healthy living conditions in the Rollberg and Flughafen areas of Neukölln, Berlin, Germany.



Ikambere

a welcoming house supporting women to overcome socio-economic and health inequalities and manage their chronic conditions, in Paris, France.



Disuguaglianze di salute

Ridurre le disuguaglianze con azioni di contrasto sui determinanti sociali

Metrics for co-creation Turin

using metrics on 1) inequalities in health and 2) empowerment as a platform for a) engaging the community in co-creating health and care services and b) to seize 'windows of opportunity' to transform the current system.



Maison de la Santé Mentale

creating a place where mental health associations come together to raise awareness in Strasbourg, France.

Poliklinik Veddel

a community health centre with a strong focus on social justice and addressing the social determinants of health, linking previously only sporadically existing network of social and health care structures in one place and politicising health in Hamburg, Germany.

Poliklinik
Veddel

Kwaito

a entrepreneurial cooperative association of 10 organizations across the region Flanders, in Belgium, each with expertise in long-term and intensive care that seeks to inspire a transition towards a new care system promoting care within social, economic and environmental sustainability projects and through innovative housing, day care, work, leisure and mobility models.



Parma WelFare

Punti di Comunità, providing support and light home care services to fragile people in the district of Parma WelFare (Italy). With 10 hubs placed in 10 different neighbourhoods (one of them in the hospital), it stimulates the activation and participation of citizens and the community, engaging of numerous public and private partners.





Piossasco Caring Community

supporting people age well through participatory approaches, integrating health and social services to work on community health and care projects, activating the community, and engaging a wide range of partners in Piossasco, Italy.



Solentra “Solidarity and Trauma”

not-for-profit organization aiming at making mental health care more accessible and effective to persons with a migrant or refugee background in Belgium while guaranteeing quality, through an integrated and community-based approach. Solentra is recognized and supported by the Flemish Government for their Caring Neighbourhood Initiative in Brussels . Their approach is unique blurring the lines between specialized and community-based care.



Vitaal Vechtdal

conceived in 2012 by a general practitioner and a director of the regional hospital in the East of the Netherlands, is a public-private partnership that has grown into a movement that aims to keep people healthy and with vitality in their community, focusing on prevention of long-term conditions.

...a bit of context on terminology: The Caring Communities initiative in Montreal included here is not the same Caring Neighbourhoods in Belgium

In June 2021, the Flemish Minister of Welfare, Public Health, Family and Poverty Reduction launched a call for ‘Caring Neighbourhoods’ that yielded 133 projects in Flanders and Brussels. During two years, a financial boost is being provided, together with intense supervision and support. The overall aim is to invest in integrated community care, where the neighbourhood becomes a place where health and care are accessible for all, where informal and formal care complement each other and where the local community and professionals work together to create a caring environment. There is great variation between the initiatives, in terms of previous experience, goals and actions, network and demographic context. But they all share the willingness to foster local alliances among all actors to codevelop better care and wellbeing in the community.

The purpose of this document

At the very core of integrated community care, lie the overarching principles of co-developing health and wellbeing and building resilient communities ([see Box p. 9](#)). Despite broad agreement around the benefits, there is a lack of clarity around how this is achieved and relatively few examples of what this looks like in practice. This is also reflected in the scarcity of literature on participatory approaches in global public health.

The purpose of this document is to support all those that are seeking inspiration and practical examples of how to foster and facilitate greater community participation and meaningful engagement of people with lived experience in the quest to improve people's health and wellbeing.

The document is organised in four main sections as follows:

- A** What the changemakers all have in common
- B** How do TransForm changemakers value and engage people with lived experience?
- C** How do TransForm changemakers facilitate community participation?
- D** New ways of working



**What do
the changemakers
all have in common?**

All changemakers share ICC's principles¹⁰ of enabling participation to co-develop health and wellbeing and building resilient communities as the basis for their practice. They have all dared to step outside of the 'normal' or traditional way of doing things, focused not on managing within the current system, but on creating new ways of doing things that worked better, in their contexts, for their people and communities. This takes time, patience and perseverance. Several changemakers noted it was important to see failing as an opportunity to do it better next time. This section describes 6 elements that all changemakers have in common.

1

Governance models that reflect wide alliances and a shared responsibility for the local community's health and wellbeing

The government, through its public authorities, remains responsible and has a prominent role in planning for and investing in the health and wellbeing of the populations it serves. However, given the current challenges we face as a society are interrelated and complex, no organization has the capacity, resources or ability to address them alone. This is why it is necessary to create and nurture cross-sectoral and interdisciplinary alliances, to join forces and collaborate with all partners public, private, third sector and civil society, including citizens' initiatives, voluntary networks, schools, social entrepreneurs, etc. It is often the case that 'gaps' in public service provision are plugged by grassroots organisations. Including people with lived experience in the governance of ICC is still uncommon, but some changemakers are leading the way.

Governance models that are inclusive and reflect a shared responsibility

Piosasco – inspired by the ICC movement and led by the Municipality, the partnership includes a public – private alliance; social and health authorities with the association “La Bottega del Possibile” as lead partner, philanthropic foundation (Fondazione Compagnia di San Paolo), Master's Course in Family and Community Nursing, Inter-Municipal Services Consortium, Residential Facility, network of associated cooperative enterprises and others. Project governance is entrusted to the coordination of a Supervising Committee (the partnership representatives) that interacts with a multi-professional micro-team. Both groups are accompanied by a “community board” made up of the operators appointed by the partners, together with volunteers and association representatives.



CALICO - began as a shared vision of several like-minded Brussels citizens and associations, who wished to come together to collectively build a healthier form of housing and living, as a community, within an urban setting. Led by a wide partnership of eight associations, health care institutions (e.g. the University Hospital provides support for the birthing and dying homes), policy makers and social enterprises the project was recognized as an Urban Innovative Action, funded by the European Union's European Regional Development Fund (ERFD). Its governance arrangements are complex and still evolving to reflect its learning journey, however, the residents in CALICO are an intrinsic part of it through two committees: The Governance Committee (for general matters regarding the project) and the Care Committee (for the community care, including the birthing and dying houses and for neighbourhood outreach).

Foundry - Each Foundry centre is operated by a lead agency that brings together local partners, service providers, young people and families. In addition, every Foundry centre engages with young people in a meaningful way through their Youth Advisory Committee (YAC). This means the young people themselves are part of decision-making at every stage of the project (design, implementation and evaluation).

aMIcittà – since the beginning, it was seen as an opportunity to create a wide network between the main public health institutions and non-profit organizations engaged in the field of mental health. The partners include associations of people with lived experience, including La Salute in Testa, a nonprofit association whose members are people with lived experiences of mental health illness and the Rete Utenti Lombardia, a regional association of people with lived experience, associations for families and carers of those with mental health conditions, as well as the Metropolitan Hospital Trust di Niguarda; Municipality of Milan and Fondazione Cariplo (main funder), 15 non profit community-based organizations, including social cooperatives, such as Cooperativa Lotta Contro l'Emarginazione and others. Partners came together with the intention of removing the fragmentation of psychosocial interventions that result from having multiple sources of funding (health services, social services, fundraising and people raising). Mutual agreements gave birth to the integrated system and to communities of practice involving experts and citizens who designed and monitored all the project activities. Despite the huge strides that reaching this level of integration entails, aMIcittà notes it can be difficult balancing power relationships between all the different entities involved.

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 and national actors are willing to foster community building and place-based initiatives. One of the key ingredients of ICC is to have support from the top-down, i.e. politicians and public entities. This makes it easier to persuade others to join (and fund) the effort. But that on its own is not enough. The bottom-up, that is the grass roots, is also the key to success. Without them, the most brilliant solution on paper will likely fail to be adopted.

ELZ Regio Aalst - a Primary Care Zone is a network of primary care providers (e.g. general practitioners, social workers, psychologists, patient organizations) in a geographically defined area consisting of one or more cities or municipalities. A Care Council manages a primary care zone and is composed of 5 clusters, i.e. care, welfare, local authorities, people with care and support needs (lived experience), informal caregivers and optional partners such as hospitals, educational institutions, etc. In the primary care zone, the exchange of information and knowledge is crucial and care operations are coordinated. Efforts are made on the basis of a bottom-up area analysis to set one or more local goals on care and welfare. The balance between bottom-up and top-down approaches is always delicate.

2 A shift in power dynamics

Changemakers recognize the need to create a more level playing field between those who currently set the agenda and make the decisions and those with lived experience, civil society, and more marginalized groups. ICC calls for distributed power - from power held by a few, to power held by all. At the macro level this means establishing inclusive processes for engagement and that decisions are made together. For engagement to be meaningful we need to first value people as the primary experts on their own lives. Without this, it becomes merely a tick box exercise. At the micro-level, changemakers transfer power from professionals to people with lived experience. Doctors, nurses and other professionals consider patients partners and vice versa. Goal-oriented care¹³ as a guide for treatment decisions is an approach that facilitates this rebalancing of power. And finally, changemakers also address power dynamics *between* professionals.

“For change to occur, we need to give up some of our power. We need to reflect on our power and our privilege. And to know that giving up some of that power is the only way for us to approach any kind of equity and social justice”

.....

Leslie Varley
Association of Aboriginal Friendship
Centres, Canada

Poliklinik Veddel and GEKO – hierarchies are dismantled through valuing everyone’s contribution equally. The cleaners and the doctors are paid the same and all decisions are made through regular assemblies with participation from all those involved. The feedback is overwhelmingly positive, a strong sense of camaraderie that comes with an alignment of values and the feeling that there is freedom to make a difference without having to ask for permission.

Kwaito’s philosophy is for the Neighbourhood Points to be owned by the community. of the welfare coordinators is one of facilitation, participation, and supporting those who need help (focus on the most vulnerable people).

Solentra – carries out Community Based Consultations to support people with migrant or refugee backgrounds with mental health needs. The Community Based Consultations focus on improving the persons’ resilience. A psychologist from Solentra together with the referrer (e.g. care organisations, schools, justice department, etc), the person and the people who form or could form their support networks, design the ‘treatment’ plan together, taking a broad vision of health. In these consultations and before an (individual) specialized treatment is started, the person is an equal and active partner in the definition of the problem and the construction of the solution.

aMIcittà - experts by experience are equal colleagues in personal health budget teams.



Poliklinik Veddel - Hamburg



Martine Vallarino and Luca Boccanegra from aMIcittà

The social determinants of health are considered part and parcel of care

“Why treat people and then send them back to the conditions that made them ill?”

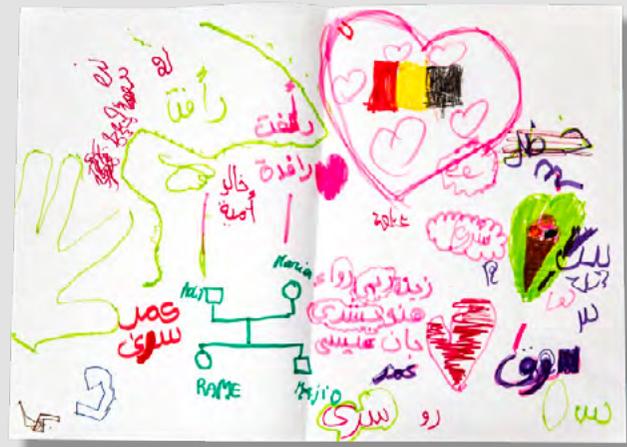
 Michael Marmot

It is well recognised by now that the conditions in which people are born, grow, live, work and age have a direct impact on people’s health. There is a crucial difference between asking people to help themselves and supporting people to help themselves. That is, people are not always able to self-care or act on care advice because they have no control over the wider socio-economic structural problems they face. A doctor might encourage someone to do more physical activity and eat a healthier diet, but the person may not have the time to prepare healthy meals or access to suitable space

and motivation to exercise. When it comes to mental health, taking the social determinants into account is a crucial part of the recovery process for those suffering from long term mental health conditions. Housing, work or training and social inclusion are amongst the objectives of a person’s life project. The management of the clinical aspects is only one of several that if considered on its own, does not lead to recovery. TransForm changemakers are all acutely aware of people’s contexts and proactively seek to improve their overall life conditions, as a crucial part of ‘care’. In fact, approaches that address the social determinants of health are in essence working for the wellbeing of all, not only those in vulnerable situations and as such are preventative in nature, serving to mitigate people falling into situations of vulnerability.

Addressing the social determinants of health

Solentra supports refugees, asylum seekers and migrants with mental health needs using a methodology they developed themselves that takes into account the individual’s context (school, socio-economic environment, federal laws and religion) and the relations between them. This ‘ecological system’ is often underappreciated or even ignored by regular social and healthcare institutions, particularly when it comes to people in vulnerable situations. The Community Based Consultations ([Box p. 29](#)) result in shared plans that often require mobilizing other stakeholders to tackle the social determinants of health. This tailor-made network of formal and informal stakeholders that comes together to address the needs of the person being supported fosters their integration into society and forms the basis for their wellbeing.



Solentra - Drawings of refugee children during therapy

Ikambere supports women in vulnerable situations with long term conditions - HIV, diabetes, obesity, hyper-tension - not only through helping them manage the medical side of things, but through addressing their broader socio-economic needs. A multidisciplinary team of social workers, therapeutic education officers, health mediators, professional integration officers, a dietitian, and a fitness coach developed an integrated community care approach in order to accompany these women towards empowerment. This methodology changes the women's living conditions, habits and behaviors through individual follow-up and group workshops designed to improve their social and therapeutic care and, ultimately, their quality of life. In order to address all social determinants of health, Ikambere has also built local partnerships with assistance services for housing, access to rights or employment to strengthen its action and now has about 30 operational partners in the region.



Ikambere - exercise class



CALICO set out to address the main challenges impacting on the health of urban dwellers including affordable quality housing, loneliness, public transport, access to green spaces. CALICO provides access to housing within the framework of a Community Land Trust, economic and social support in addition to the more direct care component, through the co-located midwife-led birthing house and end of life facility. There is a strong relationship and support from the University Hospital and allied health professionals to support people with chronic illnesses or long-term care needs to keep their autonomy in a home setting.

CALICO

GEKO and Poliklinik Veddel actively try to reach out to the communities they work with and support locals in organizing themselves as groups to articulate and advocate for their needs and problems. They also strive to identify joint solutions for struggles that were previously perceived as individual problems, for example rent increases and evictions. Poliklinik Veddel's community worker supported a group of about 100 tenants that were being evicted from their social housing building to get organized, find the support of a lawyer and hold meetings with politicians, the local press and the building owners to guarantee the building would be renovated and the inhabitants would not be evicted. They were successful.

aMIcittà directly supports personal health budget users with apartments for independent or supported living, financial support, internship and employment support, opportunities for social inclusion or socializing (free activities or at reduced prices). aMIcittà advocates for a shift in resources from mental health residential facilities (which absorb about 70% of mental health resources) to community projects, noting that with the economic resources of a residential placement it is possible to realize three or more placements in the community, to better effect.

4 Human connection and relationships at the heart of the way of working

The current health and care systems ironically were not designed to 'care'. They were designed to 'cure' as efficiently as possible. Health and care staff that often go into the profession because they genuinely want to make a positive impact on people's lives, are frustrated and worn down because they are not allowed the time or flexibility to really care for, about and with people. Their work loads mean they are forced to deal with immediate problems and struggle to take into account the wider context or the time to get to know those they are supporting. In recognition of this design problem, TransForm changemakers have creatively sought ways to build time in to get to know each other and achieve that human connection. Feeling connected, understood and supported is an important foundation of wellbeing.

“Relationships were allowed no place in the welfare state because they were thought at best not to matter and at worst to be a hindrance to social progress. A reform process that has centred on management and control has further limited the possibility of human connection within existing systems. Today the welfare state concentrates on the efficient delivery of inputs and outcomes, trapping us in the cultures and mechanisms of transaction and limiting human connection.”

.....

Hilary Cottam
Radical Help

Human connection

Ikambere was born out of the desire to welcome a community of migrant women living with HIV in Paris, to offer them a warm and friendly place where they could rest, take their medication, laugh, and cry. It was a safe space where women could bond over cooking and eating and share a word about their experience of their illness, as well as their experience of migration, which is often traumatic and violent. Without the trust and the relationships developed through this ‘soft’ aspect of Ikambere, they would not be able to provide the wide range of support they do as successfully as they do.



Ikambere



Kwaito's partner De Lovie - one of the Neighbourhood Points

Kwaito's partner De Lovie, based in an isolated part of Flanders, De Westhoek, responded to the need to breathe life back into rural villages that have suffered from depopulation and a loss of public and private services. Neighbourhood Points are developed by each community, with the support of Neighbourhood Point coordinators, and staffed by people with disabilities. These vibrant hubs host libraries, shops in partnership with local producers, cafes, mobile bakeries, play areas and activities for local children, and meeting areas that can be hired out for a range of community activities. Despite only been around for about 5 years, the initiative has already created innumerable connections and support networks between the inhabitants.

#Com.viso organizes a range of social activities such as game nights for older people, community meals, among many others, as a way to establish relationships and build trust with people, so that support can be provided when it is needed, in a more natural way. This approach serves to increase social capital and acts as a protective factor for the community. The role of the animator is crucial in facilitating and nurturing the approximation between people.

Solentra's philosophy is that it takes a society to heal war trauma. Integration into the new society, enabling the experience of caring human relationships, is a necessary condition to the (individual) cure of war trauma.

It is not only the relationship between the health and care professionals and the people they support that needs to be strengthened. The relationship between the people in the community are arguably just as important – although this is something that is still not often measured, valued and therefore invested in. This is related to the matter of access and proactive care. Despite the importance of research and of tools like stratifying the population to better target care, it is not always possible for ‘services’ to identify those most in need. People know their friends and family, the people in their neighbourhoods best. They are often best placed to identify who needs support and how. Changemakers have all come up with intuitive, organic ways to create connections with and between people. They create ‘proximity’ between people as well as with professionals, increasing the number of relationships and therefore improving their access to a wide range of support systems. Increasing social capital improves people’s ability to cope in adverse situations , i.e. it improves their resilience.

5 Merging of formal and informal care

Changemakers’ initiatives all value what would be considered ‘informal’ interventions and blend these with more formal ones. In doing so, they expand our understanding and the definition of ‘care’ and ‘cure’. The wide range of changemakers’ activities showcase what truly taking care of each other looks like, beyond the traditional medicalised concept. Some examples include Kwaito’s approach to fostering care indirectly and the Caring Communities’ peer teams.

Solentra - when creating a tailored support network around the person in need of trauma therapy, Solentra’s and the referrer’s formal networks are considered as well as the person’s own, informal networks, including in their home country, for example a grandmother/father who stayed behind but used to play a big role in the education of the child who is now a refugee in Belgium.



Solentra - Co-creative photovoice project in which young refugees (15-24 years old) explore with a transcultural psychologist and researcher the effects of the COVID-19 pandemic on their mental well-being.

Several changemakers invest in creating opportunities for leisure or social activities for people that would otherwise not have the means to access. This provides much needed respite for people who are in vulnerable situations, marginalised or lonely. The act of socialising as a way to foster connections, networks, social capital and resilience, is therefore a crucial prerequisite to our wellbeing. These more ‘informal’ aspects of care and their impact on people’s wellbeing are not often measured and therefore mostly undervalued when it comes to designing, planning or investing in health and care. And yet social networks are recognised as a determinant of health. Changemakers often take social activities and creating proximity between people as a start point to care.

This merging of the formal and informal – these new forms of caring for each other do not tend to happen spontaneously. They require a strong, coordinated and sustained drive to make it happen (including funding, leadership, governance, workforce and training, research). Volunteers also play an important role in supporting several of these projects.



#Com.viso

Volunteers – a role that helps to build in ‘time’ to the system

Volunteers, tend to be lay individuals of varied backgrounds, mostly based in the communities they serve that offer their time and support to others without pay. With relatively little training, they are able to complement the roles of paid professionals, signposting and improving access to services, particularly when there are limited resources, providing advice and supporting people in various ways. Volunteering also fosters a sense of community ownership. Attracting and retaining volunteers is something else changemakers constantly channel efforts on.



Parma WelFare

Demonstrate that ICC works better than current systems coping with crises, like the Covid-19 pandemic

“Even before Covid we had identified who was vulnerable in our community, we had supported them to remain well in their home environments... the trust was there, so they were not afraid to let us help them through the pandemic”

 Piosasco

“Community groups were not involved in planning the Covid response and this was a mistake. We knew the women we support well and they trusted us, so we were able to reach them, check how they were, what they needed and mobilize and adapt our support much faster than the health system could. During Covid, some of our funders and partners realized the importance of what we do”

 Ikambere

“We managed to do things during Covid that wouldn’t have been possible in peace times. The urgency to find the answers during the pandemic situation “helped” to develop rapid collaboration strategies that would have taken much longer in the pre-Covid phase.”

 Parma WelFare

From the start of the pandemic, Transform collected experiences and reflections of ICC practices in a series of blogs. The International Foundation for Integrated Care similarly has compiled experiences and organised webinars on the topic. Our change-makers’ experiences show how community-based care is often better placed to support people in crises situations– they know their people and how to best reach and help them.

Covid experiences

Caring Communities – caring for one another in the streets. When Covid-19 hit, many primary care clinics and shelters were dismantled, less people were showing up, hot spots for homeless people were closed (and in Canadian winters, this is deadly). The situation was dire and the current way of caring was not working. Montreal’s Caring Communities decided to expand integrated community care teams to include people with a range of experiences, including peers with lived experience of homelessness. Integration of peers helped create trust with marginalized people, establish bridges between community resources and professionals, and brought hope. As their team expanded and diversified, peers created a learning circle to learn and support each other. In doing so, they have managed to make the invisible, visible by opening the doors to a variety of peers working hand in hand with professionals¹⁴.

Even though having established strong relationships with and between people in the community undoubtedly helped manage this crisis, a protracted period of isolation makes it hard to keep the connections going. Nonetheless there were creative solutions to this.

Ikambere - Since the beginning of the Covid-19 pandemic, Ikambere’s model of community care has proved to be essential to provide comprehensive support to women in vulnerable situations. Many of Ikambere’s beneficiaries have been affected by isolation and a loss of income, which are major challenge that add to their existing social problems: women of migrant origin, with a fragile state of health, and living in a situation of great insecurity and isolation.

Kwaito’s partner De Lovie’s Neighbourhood Points were the only shops that remained open during the pandemic, as they were considered essential services.

Pioissasco focused on actions to contrast loneliness and isolation, notably during the Covid-19 lockdowns, by activating volunteers in the community to provide monitoring and care to elderly.



INQUADRIAMOCI
 FAB - EX CASERMA M. MUSSO

VENERDÌ 16 OTTOBRE
 ORE 16.00 INAUGURAZIONE

SAB 17 - DOM 18 OTTOBRE
 ORE 10-12.30 / 14.00-18.00

DA LUN 19 A VEN 23 OTTOBRE
 ORE 16.00-18.30

SABATO 24 OTTOBRE
 ORE 14.00-18.00

#Com.viso

Solentra - working in a sector that is characterized by crises in itself, Solentra’s activities are constantly adapted to the demands of the situation and the needs of the target population. During the pandemic, a stress reduction helpdesk in Arabic and Farci were launched (two major languages of the Belgian refugee population). This was replicated for the Ukrainian crisis. Solentra also trains native speaking refugee psychologists in specialized trauma treatment with the aim of improving access to mental health care.



Solentra - Group session with Ukrainian refugee children

#Com.viso’s activities had to be cancelled during the pandemic. The older people that had come to rely on the regular social contact suffered. But animators persevered in reaching out, connecting and involving them in fun ways and in so managed to make them feel less alone and supported during the worst of times. The animators took inspiration from famous paintings, matched them to the local older people and recreated the famous painting with the older people as protagonists. It became a travelling exhibit.



**How do TransForm
changemakers value
and engage people
with lived
experience?**

The right to participate in one's care is also a fundamental part of the human right to the highest attainable standard of health.

Although there now seems to be a general consensus that care should be co-produced with people with lived experience of health and social care and their communities, this is rarely achieved in practice. Research is catching up in understanding the many roles that people with lived experience of health and social care can play in shaping services and consider what supports would enable them to fulfil these roles.

There are two main aspects to valuing and engaging people with lived experience. On the one hand, it is about recognizing and valuing people with lived experience as being the experts of their own life and holding a prominent role in the design, implementation and evaluation of their own care journeys (noting that of course not everyone wants to be involved in the same way and this also needs to be taken into account and approaches adapted). Another important role played by people with lived experience is that of an expert in a particular condition/ disease/ situation of vulnerability that provides support to other people in similar circumstances as a peer.

People with lived experience are a valuable resource – they are able to support their peers in a way that professionals are not able to. They understand the person better and can make a connection at a different level which makes it easier to then find the right way to support them. Their contributions are complementary to that of professionals and when they form part of a multidisciplinary team, they quickly become invaluable. Aspects such as payments/ salaries and training are important, as they would be for any other expert.

Experts by experience – an innovation in mental health leading the way

It has been 45 years since Franco Basaglia's revolution in how we view and support mental health started spreading around the world. Grounded in the recovery paradigm, one of the main innovations was the active presence of people with direct experience of mental illness (experts by experience or peer supporters) who become active and responsible subjects instead of being a "care recipients". The focus is on coproduction of care and since then we have come a long way in recognizing that people from all walks of life and with all sorts of experiences are best placed to support their peers. Changemakers have been expanding this role both within mental health as well as to cover other life conditions.

The World Health Organization is currently co-creating a **framework for the meaningful engagement of people living with non communicable diseases and mental health conditions** with a planned release in Spring 2023.

People with lived experience can also include families and/or carers. For example, Centro Paideia involves siblings in the activities and they often times end up becoming volunteers supporting the programme.

We asked TransForm changemakers how they engage people with lived experience and this is what they told us.

1 Empowering people with lived experience, amplifying their voices at all levels

Changemakers identified three main ways to achieve this:

a - Connecting people with lived experience with each other, forming networks

There is always power in numbers, and it is not different in the case of people with lived experience.

Power in numbers

The Rete Utente Lombardia , an association of experts by experience that was founded in 2014 and part of the **aMIcittà** initiative, has achieved incredible things by having come together. With the motto: ‘nothing about me, without me’, the association provides the opportunity to people with lived experience to make choices about their own lives through managing local mental health projects (e.g. La Salute in Testa) while also working to create a true shift in power through its political role .

Centro Paideia connects families that face similar situations because it is empowering and helps develop people’s self-efficacy, while concurrently enhancing the resources of the community to provide support. For siblings of children living with a disability, meeting and spending time with other siblings in similar situations makes them feel less isolated and supported.



Centro Paideia - sibling activities

b - Supporting people with lived experience to participate in decision making

There are a wide range of reasons and motivations why people with lived experience may want to get involved in decision-making. It could be to address discrimination, encourage services to reflect diversity of communities, to change professional and organizational practices, to prevent poor care in the future, to improve access to information, treatment / support patient choice, to meet a current gap in service, among several others. Not everyone wants to be involved in the same way or at the same level either.

At the moment, there is a gap in knowledge and research around how to best support people with lived experience to become agents of change. In fact, a piece of research by the Universities of Birmingham^d, Toronto and Leiden University Medical Centre is currently taking place that involves interviews of people with lived experience who have been able to influence integrated care at a local or national level in different countries in order to understand how they see their roles and the barriers and the enablers to their involvement. Some of the findings on enabling their involvement include:

d) For further information contact Professor Robin Miller, University of Birmingham (email: r.s.miller@bham.ac.uk)

The Lombardy Regional Course for Experts by Experience

The first regional course for experts by experience in Lombardy took place in 2019. It was funded by the Ministry of Labour and Social Policies and promoted by the Lombardy Region - DG Social Policies, Housing and Disability. The participants of the course were supported and referred from various mental health centres, associations and cooperatives. In addition to the theoretical, class-based content which covers topics such as about mental health conditions, pharmacology, and experiential training techniques, group management activities and self-help tools, the experts by experience also had to complete an internship in order to obtain the certificate to be considered a qualified expert by experience. This entailed around 200 hours of a work experience. This is not currently a nationally recognized qualification although work is underway to achieve this. Following the course, some experts by experience were selected to be part of the aMIcittà project. Participants' experience was studied through focus groups facilitated and recorded by a Master degree student from the University of Pavia. A booklet (in Italian) has been published about this innovative course, including its curriculum, and is available upon request.

The role of experts by experience is not only about having lived experience of mental illness, but is also a result of the personal recovery process, combined with specific training and work experience in the mental health field as a carer. It is an ongoing learning process.

“One of the most important things was that the training helped to lead to work placement. In this case with aMIcittà”

.....

Luca Boccanegra
expert by experience

- Investing in people over the long term to grow their confidence and communication skills
- Opportunities for paid roles – so that people do not have to rely on their own income
- Influential leaders / clinicians who will support and invest their time and energy, and develop a collaborative relationship
- Embedding systems and structures to facilitate engagement including recognized and skilled points of contact
- Sitting around the table as equals to develop an initiative
- Shared learning opportunities with service leaders
- Legal policy responsibility to involve people with lived experience
- Local areas / national governments creating opportunity to shape policy / programmes

The way people with lived experience are currently supported and/or manage to participate is very much ad-hoc. They tend to learn by doing – most are ‘thrown in the deep end’. This is very different to professionals who get trained and gradually exposed to practice settings. There are some examples of people undertaking courses with professionals and bespoke learning programmes for people with lived experience.

Based on aMiccità’s experience, some of the most effective ways to support experts by experience to become change agents are providing low-barrier participation in training courses, volunteer opportunities, supportive employment and, ultimately, the experience and opportunity to become a unionized staff member.

People with lived experience as part of governance structures

In **Centro Paideia**, parents form part of the Steering Committee. In Foundry, the Youth Advisory Committee is a key part of the governance.

ELZ Regio Aalst – people with lived experience – in Flanders called ‘people with care and support needs’ - are represented in the Care Council, which is the governing body of the primary care zone, a non-profit organization. They also take part in a working group, focusing on the needs and preferences of people with care and support needs and are able to impact both on policy and on concrete field projects. Members of this working group can be professionals, e.g. staff members of an informal care organization, as well as people with lived experience. A long-term policy on how to strengthen the voice of people with lived experience in the Region and embed them in the functioning of the organization is undergoing consultation. It is recognized as essential that the ‘what’ and ‘how’ are defined by the people with lived experience during this participatory process. The outcomes will be implemented in 2023.

c - Engaging people with lived experience in research and evaluation

The seventh principle underpinning ICC is that of monitoring, evaluating and adapting ([See p. 9](#)). The 7 effectiveness principles serve as an open framework to guide those seeking to implement ICC. One of the main issues encountered in the field of measurement and evaluation is how to measure the things that actually matter to the people an intervention is meant to benefit as opposed to the information that funders request. Changemakers all recognise that evaluation for the purposes of learning and adapting is indeed an important part of transforming the system and the way we value people with lived experience. Several have either carried out research and evaluations or are in the process of doing so. And yet this is perhaps one of the least developed areas amongst the innovative initiatives. It is also the area with the most potential in future. There are a several types of evaluation approaches and methodologies available.

Participatory and action-oriented approaches to research and evaluation

Poliklink Veddel set out to research the social determinants of health in partnership with the community, through hiring community researchers as part of the research team. There were 3 researchers with an academic background and 8 researchers that are experts in their communities. At the beginning of the project, the community researchers felt they were inputting into the work of the academic researchers, but over time an ownership shift took place, leading to a true partnership. The community researchers have taken a pivotal role both in setting the research agenda, the interpretation of the findings and the implementation of resulting ideas or solutions. This approach not only shows that it is possible to carry out research differently, to partner with the people it is intended to benefit, but also that it is an extremely effective way to transform the way we design care systems.

Pioiasco carried out what is termed an empowerment evaluation, where the aim is to increase the probability of achieving program success by providing all stakeholders with tools for assessing the planning, implementation, and self-evaluation of their program, and at the same time mainstreaming evaluation as part of the planning and management of the programme. It includes both a process and outcome evaluation combining quantitative and qualitative approaches. On the quantitative side, internationally validated scales were used to assess the risk of fragility, autonomy and perceived quality of life). On the qualitative side, focus groups with all those involved in the project, including the micro team, expert walkers, voluntary workers, beneficiaries, as well as individual interviews with beneficiaries and stakeholders. The evaluation's possibly most innovative aspect is that it successfully measures the things that matter - benefits that as of yet do not tend to be covered through evaluations such as social capital. The indicators for this include: the number of beneficiaries that have become volunteers, intergenerational networks created, spontaneous self-help groups, political commitment of stakeholders and the social and economic capital generated. The report is available in Italian upon request.

“Developmental evaluation is an evaluative approach that supports the creation and implementation of dynamic, complex, and innovative interventions with the capacity for real time decision-making and course correction”

Patton, 2010

A developmental evaluation of Foundry

Developmental evaluation (DE) is time and resource consuming. Foundry employed a full time DE specialist and two part time assistants. Information must be shared throughout the process and there is a need for flexibility, reflection and adaptation to reflect the findings.

It was clear from the beginning of the proof-of-concept period that Foundry could not be understood simply as an intervention within a specific, defined, and bounded “system”, or accurately represented using a traditional program logic modeling approach. Rather, Foundry must be understood as an effort to transform existing the policy, service, and support landscape for young people and their families in BC to create a new system of care that is best regarded in light of understanding the emerging behaviours of a complex adaptive system. These two concepts anchored the developmental evaluation and provided a theoretical foundation for assessing the adaptive development of the Foundry movement as a whole.

More than 150 ethnographic participant and nonparticipant observations at Foundry central office and at 6 Foundry sites, document analysis, semi-structured individual and focus group interviews were carried out over 2 years. Semi-structured individual and focus group interviews were conducted with approx. 115 individuals including: Foundry Central staff, Governing Council, lead agency personnel, partner agencies, leadership table partners, youth and family advisors.

Throughout this evaluation, attention was paid to the ways in which core values and principles were articulated, evolved, and consolidated between and among actors within the Foundry movement in ways that subsequently provided a shared language and set of commitments to build a different kind of system of care for young people and families. This, in turn, mobilized the necessary resources (including the political will) to achieve system transformation within and beyond youth and family-serving administrative and funding silos.



Centre for Health Evaluation and Outcomes Sciences team

d) People with lived experience as the teachers

During the aMIcittà project, experts by experience were engaged in delivering lectures and seminars during the course of Clinical Psychology at the University of Pavia (inspiring some thesis projects as well).

Maison de la Santé Mentale in Strasbourg also is working on having a People's University in Mental Health where the plan is to have professionals sharing information with the public, but also where experts by experience then lecture the professionals and academics.

Ikambere has a successful education programme for health professionals including for medical students at La Sorbonne.

2 Creating spaces and opportunities for people to meet in a safe, non-judgemental, and convivial way

Several changemakers support people who experience isolation and stigma. Community and belonging are fundamental to people in general, but particularly to those who experience being made to feel like they are excluded. Everyone has an inherent need to be seen, heard, understood and respected. Providing a safe space with like-minded people who understand each other's challenges and see each other as their whole person – without judgement is crucial. Connecting with others is therapeutic in a way. This often does not require development of new spaces, but rather the facilitation of access through the considered use of existing spaces and services in the community.

TransForm changemakers have succeeded in generating opportunities that encourage people to naturally come together and connect. Supported by community workers and volunteers, they facilitate all sorts of activities that make people want to join in and over time, people begin to form relationships and support each other. The role the community workers and volunteers in this process should not be underestimated. Facilitation and follow up is crucial and it requires a particular range of skills as well as investment (see workforce section for more information on roles).

Spaces

Maison de la Santé Mentale has formalized an agreement between the local mental health associations, the Mental Health Council, and other mental health players in Strasbourg – with the vision of creating a safe, non-judgmental space for people to gather, seek advice and support and to act as a ‘lab’ for new ideas in anything related to mental health.

Pioassasco’s project highlights the importance of identifying physical spaces, where social activities, services and volunteering opportunities happen there, eventually becoming places recognized by the community as hotspots of the territory: even the Elderly Facility became open to citizens, families, caregivers.

Centro Paideia had the vision from the beginning to create a space that was inclusive, part of everyday life, where families from all walks of life could share generative experiences independently from the presence of disability of their children. This was so successful that many people who spend time at the Centre are not aware that it (also) provides specialized support for children and young people with disabilities.

Kwaito’s neighbourhood entrepreneurship initiatives are based on physical meeting points – Neighbourhood Points that are open to everyone in the community – not only those in need of direct care - and where all activities are organised in co-creation with the community. In this way Kwaito reaches out also to people who are not their target groups, such as people in vulnerable situations (e.g. experiencing loneliness or poverty).



Centro Paideia - kids play area open to the community

Solentra carries out community consultations in places familiar to their target population that are conducive to care e.g. social welfare institutions, schools, sports clubs, etc. This helps avoid the stigma of “psychiatry”. Solentra does not ‘create’ safe spaces per se, but rather mobilizes and support all kind of organizations that are relevant to the recovery process. An example is the partnership with a museum in Brussels to co-design art-workshops with and for refugee-kids in a way that was sensitive to trauma, provided interpreters. Solentra accompanied the process to provide reassurance.

3

Time to listen, get to know each other and build trust

There is a strong emphasis on ‘active listening’. This is not something that is merely intuitive. It is a skill. Listening is often the first step in helping someone – the sense of truly being heard is already empowering. Of course, this needs to be followed through by supporting the ability to take action. Taking action, over time (recognizing that there will be failures and that’s ok) is what ultimately leads people to improve their confidence, their sense of agency, and builds capabilities to keep healthy. The skill of active listening is also a crucial part of adopting goal-oriented care - an approach which uses patient priorities, or goals, to drive how care is delivered¹³.

Goal-oriented care

Poliklinik Veddel developed their own shared-decision-making concept that includes the idea that any medical consultation comprises two experts - one expert for medical and scientific questions and one expert for the living conditions of that patient. In order to obtain the best individual treatment both sets of expertise have to be valued equally. In that way patient and health care provider come up with a treatment plan together that is monitored down the line and maybe corrected by both experts.



Getting to know each other and building trust requires everyone involved to have patience and persistence and to acknowledge and celebrate each achievement, small as it may seem – both at the individual and the community level.

“Let us be satisfied with fixing a few things. A few things...it is already a lot. One thing fixed, changes another thousand”
.....
Parma Welfare

“One of our campaigns in the region, ‘give your life a bit of health’ and a lot of bits together end up being your whole life. So take small steps, and little by little, as you experience the success, you manage great things”
.....
Vitaal Vechtdal

The power of listening and of people being able to tell their own stories is well understood in the psychology discipline, but not so much in the rest of health and social care. TransForm changemakers understand that caring is an art – one that requires a combination of knowing how to listen, of being able to relate and of knowing when and how to help. Several changemakers noted this is resource intensive in the sense that it takes time and this needs to be built into the system. The time to listen, get to know each other and build trust is also necessary when it comes to professionals working in an interdisciplinary and integrated way.

Changemakers are also proactive – they reach out to people, rather than always waiting for them to come.

Active and proactive listening

Parma WelFare –Community points are spaces in 10 different neighbourhoods in Parma that are open to everyone free of charge. The premise is to welcome and listen to anyone that walks through the door. Volunteers offer information on local opportunities and services, they organize activities and small solidarity actions that foster social cohesion within the communities and increase social capital and resilience.

“We are there when we are needed”

Centro Paideia – the start point, when a family arrives at the centre for the first time, is dedicated/ active listening. Active listening and collaborative relationships represent the basis to promote empowerment and self efficacy. Parents are also actively involved in the rehabilitation sessions, so that they can work on the generalization of learnings.



Parma WelFare
Community Point San Leonardo



Kwaito's partner, De Lovie - at work

Kwaito's partners have developed expertise over the years on discovering talents of all people involved (especially the most vulnerable ones) and on connecting them with the needs of the neighbourhood. The starting point for this is always taking time to listen, observe, being there for each other.

Piovasco – in the face of a growing number of older people that were socially isolated, rather than carrying on as usual, the lead partners decided to put together a micro-team made up of community nurses and social workers to visit over 800 older people in the city, in their homes to ask them what ageing well looks like to them. The home visit is moment dedicated to active listening of the person’s problems, needs, but also to value their own resources. Active listening is a fundamental tool for the professionals. The team used international validated tools that focus on the resources of the person. Based on the information gathered, the micro team develops plans together with the older person and with the community board they implement a range of activities in and with the community, creating greater social cohesion.



Piovasco

4

Inclusivity – language and culture



Centro Paideia - inclusive library

Several changemakers noted the importance of language when it comes to engaging and building trusting relationships with people with lived experience. It is about respect and about acknowledging each other as equal partners. The main principle is to always recognise and refer to the individual as a person rather than their condition. Another aspect of this is cultural awareness and sensitivity. Ethnically, culturally and linguistically diverse communities often experience difficulties in accessing appropriate health services because of physical, cultural, psychological or financial reasons. Also, culturally diverse patients are often disadvantaged in mainstream systems because they are

“We can never become truly competent in another’s culture but we can demonstrate a lifelong commitment to self-evaluation and self-critique”

 Minkler

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.

Part of what helps to shift to a more respectful and inclusive culture is:

- a having diverse professional teams (for which of course it is necessary to remove barriers to accessing training, education and validation of certifications)
- b having people with lived experience as part of the teams ([see Box p. 19](#))
- c having people with lived experience / experts by experience as teachers of professionals ([See p. 35](#)).

Culture and language

Solentra - culture and language are the main obstacles to equal, effective and quality mental health care for people with a migrant or refugee background. Mainstream mental health services rarely have interpreters available and often rely on volunteers or family members to plug the gap. This is not appropriate in the context of supporting people that have undergone trauma. Employing interpreters and psychologists of diverse ethnical backgrounds helps improve access and guarantee quality of the services. The costs of this are covered through Solentra's fundraising activities. Solentra has also designed an internal training program on transcultural psychiatry and psychology, since this is not taught in Belgian universities.

5 Recognising that everyone has something to contribute

Changemakers value each person and their experience – they believe everyone has something to contribute and provide the opportunities for them to do so.

The different roles of people with lived experience

Centro Paideia enables families of children with disabilities to develop an active role in the definition of their own choices and priorities: decisions that best fit the needs, strengths and abilities of all involved are made together and families are considered partners and experts on their child's wellbeing.

aMiccità - five experts by experience were employed (and remunerated) to support the community personal health budget beneficiaries in building creating their individual plans and tailored interventions. With the ability to empathize and 'tune in' to the experience of someone in need of mental health support, in a way that professionals cannot, experts by experience form part of the micro team that aim to activate people's primary social networks. They are considered 'natural facilitators'. Experts by experience were also involved in project governance, i.e. project management, stakeholders meetings and community awareness and activation meetings. The experience brought by the peers, complemented by the specific training they received help professionals gain new perspectives and enrich their professional and organizational culture. This way of working helps to blur the lines between those who receive care and those who provide it. Thanks to their role, people with mental health conditions and family members experience a new type of therapeutic alliance and shared knowledge, aims and responsibilities.

"we recognize they have active resources, and sometimes they only need to be supported to strengthen their resources, capabilities and trust in themselves"



Centro Paideia

Kwaito's– employs people with intellectual and multiple disabilities, with the belief that each one is creating value and is able to participate according to their talents. After involving all local stakeholders, by detecting the needs of the neighbourhood, Kwaito supports the most vulnerable ones to playing a key role in their own neighbourhood (cleaning up litter in collaboration with environmental services, helping out in the cafeteria for the local playing card club). Kwaito is an instigator of a social movement towards a society where everyone cares for each other. The concept of neighbourhood entrepreneurship is different from that of a caring community in that the start point is entrepreneurship (the socio-economic activities) which facilitates several indirect ways of 'caring'.

Solentra employs interpreters from the various target groups. These are often people that have experience of war and of being uprooted but are not experiencing trauma themselves.

Caring Communities – Peers with significant lived experience (of chronic diseases, homelessness, migration, mental health, self-harm, matters concerning youth health, women’s health, indigenous health, aging, and end-of-life) often paid members of the integrated community care teams. They coach other patients in recognizing their own strengths, to achieve their life goals, at their own pace. Peers are “bridge makers”, facilitating trust-building, communication and collaboration with clinicians and community members. Caring Community builds on the assets that already exist in the community: linking existing peer-programs, connecting primary care teams and community organizations to create environments where we “take care of one another, based on the knowledge of all”



Antoine Boivin, family physician & Ghislaine Rouly, patient partner

A significant proportion of **Ikambere**’s team are former beneficiaries who are keen to give back. Many are employed, as health mediators. These undergo a health mediator course. Others are volunteers or simply join in the daily activities. This makes it possible to create a bond of trust between the current beneficiaries and the team. Ikambere aims at fostering links between older women who have benefited from its support in the past, and the newly arrived beneficiaries who are often younger and more vulnerable, struggle with accepting their disease and seek wisdom in comfort in women who have been through similar experiences.

6 What are the benefits?

The lack of research into the benefits of meaningful engagement of people with lived experience certainly remains a barrier to the mainstreaming of integrated community care. Changemakers’ experiences help us understand what the benefits might be. The emerging hypotheses are:

- **Empowering people to become agents of change can lead to improved decision-making.**

Involving those that are experts in their own conditions and lives in decision-making at all levels:

- In decisions about their own life (e.g. through goal-oriented care)
- forming part of integrated community care teams, complementing traditional professional interventions
- informing the design, implementation and evaluation of health and care services (e.g. through inclusive governance structures)

is likely to lead to more effective interventions. This in turn could lead to improved outcomes around for example, health, quality of life, access and experience of care.

- **Developing people’s own capacities** to care for themselves and to flourish, as well as **people’s capacities to care for each other**, likely acts as protective and preventative factors and could lead to less of a need for complex, more expensive support further down the line. The other aspect of this is that in recognising people as a source of knowledge and creativity, the wider system should benefit from the **additional resource and abundance created**.
- Engaging and amplifying the voices of people that tend to be marginalised and those in vulnerable situations will likely lead to a **reduction in health inequities**.
- Fosters a positive cultural change, towards a more tolerant, inclusive and resilient society.

Measuring whether the implementation of the approaches and activities outlined by TransForm changemakers in this document lead to these expected benefits or not, would contribute to our understanding of the benefits of integrated community care in a more tangible way.

The neighbourhood initiative ‘Den Hannekesnest’ was born out of the opportunity to lease the grounds of a church in Evergem, Flanders. It is a place where people supported by and involved with Kwaito’s partner Obra/Baken (now Voluit) meet and create together. It includes a neighbourhood bar, a shop and hosts a wide range of activities.

The focus is on encounter, cocreation and inclusion in this continuously developing neighbourhood initiative.





Q

**How do TransForm
changemakers
facilitate
community
participation?**

Building resilient local communities implies continuously asking what kind of life people want to live and collectively reflecting on what is required to achieve it. Community participation is crucial to building resilient communities. 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. Social or community capital needs to be built at a local level to ensure that policies are drawn on and owned by those most affected and are shaped by their experiences. It is important to note that communities are not always positive (e.g. fascism). Hence social capital is not 'good' by definition.

We asked changemakers how they facilitate community participation as a part of building more resilient communities and here is what they said.

1 A shared understanding of the local context, resources and needs

In the same way that at an individual level, it is important to take the person's goals and strengths as a start point (goal-oriented care), changemakers all take as a start point the community's strengths and needs. This takes time, is an ongoing process (not a one-off exercise) and also depends on the complexity of the project.

Several changemakers involved the community in a mapping exercise at the start, to create a shared understanding of the local context, resources and needs. Different methodologies have been used. At its simplest, the process involves interviewing local stakeholders and organising the resulting information in an excel file that can then be accessed by the relevant partners. Importantly, the focus of the mapping needs to reflect what the community is seeking to achieve or the issue it is seeking to address (e.g. social isolation / loneliness) rather than just a map of the institutions or organisations that exist in the local area. At the more sophisticated end of the spectrum, comprehensive research projects on, for example, their own particular community's' social determinants of health can be carried out by the communities themselves

CALICO's journey

CALICO's founders started thinking about the concept about 30 years ago, together with some of the inhabitants. Over a period of 8 years they carried out meetings with citizens, ergotherapists, palliative care, nurses, doctors, and many others to think about how to create a place that fosters solidarity and where people can live and support each other throughout the journey of life, including birth and death in a home environment.

through community researchers. These are people from the community that take on a researchers' role, initially supported by academic researchers. Somewhere in between is the bringing together of all the relevant stakeholders in a particular locality and through group discussions, identifying together what the main issues (the compelling case for change or 'burning platform'), the vision, potential solutions and priorities are. Even though technology probably exists that supports this mapping process, none of our changemakers made use of any expensive or complex IT solutions. The focus is on getting to know each other, coming together to find common ground and identifying how to help one another. A useful and well-known methodology for this is the ['world café'](#) facilitated by professionals.

Data is a powerful tool to get the conversations started. But also, the merging of data sets to obtain useful information on the current status of health and the issues faced by a particular community.

Understanding the local context

Kwaito's partner De Lovie – The concept of Neighbourhood Points was born after a large mobility survey in 'the Westhoek', a very rural area of the Western part of Flanders. The survey showed that due to a lack of social and economic infrastructure, people had no choice other than to travel to the closest city for their shopping or to access activities and services. For people who rely on public transport or the help of volunteers, this can be very problematic. De Lovie carried out a 'door-to-door-survey' to determine the socio-economic needs: delivery of bread and pastries seemed to be the top priority, followed by vegetables and fruit. But also, there was demand for a community center, a place where all neighbours could meet, have a coffee and a chat. Based on these needs, De Lovie opened the first Neighbourhood Point in 2017 in a former restaurant. This became a platform for a wide range of different initiatives and it employs people with intellectual and multiple disabilities, supported and cared for by De Lovie.

In **Turin** the research started from studying current situation and needs. The metric on inequalities in a powerful tool to reach consensus among a wide range of stakeholders as to what the problem(s), priorities and potential solutions should be.



Changemakers Prof. Costa and Di Monaco using the metric on inequalities to reach consensus

GEKO conducted a comprehensive social space and needs analysis, mapping existing health, social care and voluntary structures and actors in the neighbourhood. and inviting them to focus groups to discuss needs, care gaps, resources and wishes. Since then, GEKO have actively created networks and cooperative relationships with many of these actors and organisations and participate in local network meetings and neighbourhood committees.



GEKO

#Com.viso started with a research phase that included interviews with institutions, public services, and associations. Using the World Cafè approach, they were able to gather information on the needs and wishes directly from people living in the community.

Centro Paideia - The project was based on a profound understanding of the needs and desires of the families that were being supported. They were the main source of knowledge and inspiration and were involved in the design and implementation of the project from the start.

Solentra has followed a similar approach to Poliklinik Veddel and GEKO's, employing local community researchers to work with community stakeholders in a neighbourhood in Brussels to understand the human topography – how people relate to the neighbourhood, to each other, what resources there are, what the accessibility is like, the specific problems, needs and desires of people in the community. This approach takes time, but once trust is built, the process of co-identifying potential solutions and priorities can begin. This sort of 'mapping' represents a shift from 'doing to' to 'doing with'.

Foundry is organized as a network of community-based health and social service centres and online tools and resources for young people ages 12-24 and their families. These networks are very much grounded in their communities. Each local Foundry Centre then feeds information to Foundry Central so they can continually adapt their support according to evolving needs.

Piossasco: public services, professionals and other actors come together to initiate processes of change, getting beyond standard procedures that give only standard and scattered answers: there are no standard needs, people need to be considered as unique. The element of proactivity is fundamental, as well as a system on monitoring and evaluation based on action-research, mapping out inequalities and resources to empower the community.



Piossasco



Vitaal Vechtdal

“the work at the start was top down – it involved programme and project leaders from insurance companies, municipalities and the hospital. The first couple of years these people involved were excited about the potential. But then we realized ‘this is not working’, our intentions may have been good, but our start point was wrong. We were essentially having meeting with each other, but nothing was happening at the community level. This is when we realized we had to change. We started over, identified who the local players are and set out to listen to those that are already active, e.g. local villages who had organized walking groups, primary schools, etc. We showed them the data on the local population, we discussed the problems plaguing them and slowly people started coming on board. Now we have a range of activities like smoking cessation, cooking healthy recipes together, walking groups older people activities where we then share info about healthy ageing...the community has finally come together working towards the common goal of being healthier”

.....
Vitaal Vechtdal

2 Bringing everyone on board

Changemakers are all transforming people’s lives, while at the same time working to transform the system.

Transforming the system

Poliklinik Veddel and **GEKO** both have a strong emphasis on social justice and ‘politicizing’ health, meaning they are trying to change the way the current German health system works so that it is less focused on profits, more accessible and people-centred, and less siloed. The movement is growing and now there are several community health centres throughout Germany. Through the creation of the Poliklinik Syndicate, they are able to lobby at regional and national government levels. Last year, for example, the Berlin government coalition included in their manifesto the plan to create a funding model for integrated care centres modeled on GEKO.

aMIcittà – a specific taskforce was created to promote the extension of the community personalized health budget to the whole region of Lombardia. In recent years, a representative of the experts by experience was included in mental health and social policies committee both at local (Municipality of Milan) and regional levels to secure more relevant and impactful policies. The presence of experts in institutional settings such as political committees, university training courses and research projects represents one of the most significant achievements of the project, although there is still a long way to go to embed the model into mainstream services.

Solentra brings a human rights perspective to the mental health sector – something that remains uncommon – and works to transform main stream services so that they are more accessible and effective for everyone. Solentra is embedding transcultural psychiatry (a specialty that recognizes culture, language and social networks as part of the healing process) into existing mental health networks through partnerships to pool resources and activities, improving the chances of integration and connection for migrant children, young people and their families . Solentra also carries out a range of capacity building activities and lobbies for the academic recognition of transcultural psychiatry/psychology as a specialization in the curriculum of future psychologists and psychiatrists.

Kwaito is currently focusing on ‘neighbourhood-oriented entrepreneurship’ which entails local residents and stakeholders coming together to develop sustainable socio-economic activities in response to the local needs. Kwaito’s members (welfare organizations) support people with disabilities to take up a role that is based on their talents and provides care when it is needed. Care is provided in an indirect, preventive way, using the activities as a gateway for establishing relationships. Every stakeholder has an active role according to their talent, allowing society to move away from labelling people. Based on knowledge sharing, Kwaito’s 10 members, geographically spread across Flanders, do business together, locally and supra-locally and also lobby for policy changes to support this new way of caring.

Both EZL Regio Aalst and Vitaal Vechtdal described having begun with a mandate to improve their communities’ health yet struggling to secure the community as partners. **Local leadership** is crucial, to champion the vision while allowing for experimentation, giving permission to fail. Inclusive local governance helps to build trust and a sense that people can influence change. An important process is that of identifying, together with the local community, a ‘burning platform’ – a problem that feels important, relevant and urgent. This creates the momentum to rally together to jointly identify a **shared vision and solutions**. It is important not to reduce participation to consultation (with representatives). Changemakers work continually to build connections and alliances and to make sure every partner remains connected to the vision. A range of different methods and tools can be used to achieve this. Our changemakers noted the following as useful:

- **social design techniques**¹⁵, help to find common ground amongst partners with very different backgrounds. Innovation is approached from a human-driven way of design thinking, starting from the needs and requirements of users and looking for solutions together with these users and other stakeholders.

- **Use evidence to inform and facilitate the conversations** and reach a common understanding and agreement on what the problems are and come up with ideas on how to address these. The city of Turin in Italy focused urban policies on health equity based on evidence and stakeholder engagement¹⁶. To be able to do this you need to have good data and the capacity to analyse it in a way that can be transmitted clearly and powerfully.

- **Participatory action research approaches** - aims to create positive change, and allows the citizens voice not only to be heard, but to be involved as well. Research activities carried out within the Solentra Academy often take the form of action research with the double aim of clinical intervention for the participant on the one hand and amplifying their voices on the other hand.
- **SCIROCCO** – Scaling Integrated Care in Context¹⁷ as a tool to help build consensus amongst wide range of stakeholders. ELZ Regio Aalst and other primary care zones in Flanders have or are using this joint assessment tool to identify the maturity to implement integrated care, identify strengths, weaknesses and reach consensus as to the priority areas of focus.

Vitaal Vechtdal designs communities of practice following social design methodologies, such as the Reframing Method developed by TU Delft in the Netherlands. Designing in the widest sense of the word, is about changing existing situations into preferred ones. The method focuses on the question which experiences and interactions are meaningful to people in the future world and how to proactively respond to future opportunities rather than reactively to the problems of today.

Turin's metrics for co-creation:

In Turin, Italy, key community actors and decision makers from the local city governmental and private institutions and civil society organizations came together to foster intersectoral actions to tackle social health inequalities, using the metric of health equity as a start point for discussion and co-creation of solutions. Since then, a metric for empowerment has also been developed and is currently being tested. What these metrics do, is enable all stakeholders to identify together what the vision is and priorities actions to achieve it, as well as trigger a cycle of change in a participatory way.

Given there is an increasing interest in ICC from policy-makers in Europe and that the likelihood is that several future ICC initiatives may be policy-driven, it is useful to note that an important role to ensure community participation is that of change management to support the period of transition.

3 **Creating warm, welcoming, inclusive spaces, open to the community**

In much the same way as changemakers create spaces and opportunities for individuals to meet and be supported in a safe and non-judgemental environment, they also create inclusive spaces that are open to people from all walks of life and foster a sense of community. The welcoming, pleasant places created is one of the most striking features that most changemakers share – this is of course because it is the first thing one can perceive when visiting each initiative. It is visual and palpable. As mentioned previously, this is not always about building new spaces but is often about the use and sometimes repurposing of existing spaces in the community.

A crucial aspect of inclusivity is how changemakers find ways to proactively reach out to people who may be on the margins or excluded from society, in this way ensuring the place is truly for the community in practice, not only in name. This is a way to emphasise the importance of context and place to an individual's wellbeing, but also is an indirect way of 'caring'. Our daily interactions and relationships have an important impact on our sense of wellbeing. For spaces to be welcoming to everyone, changemakers consider the physical aspects of accessibility, such as location, ramps and toilets, but also the non-physical ones, such as ensuring the place is not stigmatising (e.g. Solentra using sport facilities), that the name is non-stigmatising (e.g. Foundry was a name selected by young people themselves. They indicated they did not want the name to include any reference to mental health).

Inclusive spaces

#Com.viso converted the old military barracks in the remote mountainous area of Monviso, in the Northwest of Italy, into a spectacular community space that includes a public library that has no barriers to entry, includes computers for anyone to use and pristine public toilets. It is collocated with the local high school and as such is in a prime position in terms of accessibility for the young people in the area. A wide range of associations that work with youth in the region have offices in the building. Other facilities include ‘spazio approssimazioni’ where young people can hang out and a lab to come up with ideas they may want to pursue. An ‘animator’ is at hand to help facilitate ideas young people may have about projects they may like to explore or connect them to relevant services that are available. There is also a professional recording studio available for the young people that they designed themselves, a kids’ zone and much more.

aMIcittà makes use an existing multi-purpose building called “Biblioteca Inclusiva” that includes a café/ bar/ restaurant with a kids’ playing area, an animal farm, performance space, as well as an inclusive library where activities are held around the topic of mental health with schools and others. The use of existing spaces by the project helped make the community a more inclusive one and to reduced stigmatisation of mental health.

Parma WelFare’s Punti di comunità are free spaces that include kids’ zones, libraries, cafes, and private listening rooms.

Piovasco achieved the extraordinary task of opening up the local care home and turning it into a community space, where older people happen to also live. They also invest in other community spaces such as parks, local education premises, bowling alley, etc.

Centro Paideia is open to all and hosts a wide range of activities for the whole community. There is a pool that serves the double purpose of being part of the therapeutic activities for children living with disabilities, as well as a public pool. Children with disabilities love to spend time there because it is a place where they do not feel judged.



Centro Paideia - inclusive library activities

Kwaito's Neighbourhood Points are warm, safe and comfortable havens in communities where everyone is welcome and seen as capable of playing an active role in the activities. Every point is set up in a different context and meets the different needs of the neighbourhood. One example in a rural environment where there were scarce public places to meet (e.g. no cafes, libraries, etc). Each Neighbourhood point run by De Lovie includes **1)** A local farmers' shop: vegetables, fruit, meat, dairy produce, bread and pastries with special attention for short chain between producer and consumer. **2)** A meeting place with a social function : just to catch up or to ask for a specific service **3)** A mobility junction where different initiatives regarding mobility come together: a location for carpooling, borrowing a cargo bike, renting an e-bike and a bicycle repair shop. All of this, to connect people and make a warm and caring neighbourhood. This is a good example of social embedding of care: whereby starting out from the social and economic needs in the neighbourhood, care can be provided where it was needed. In addition, it creates mutual dependency.



Kwaito - social embedding of care

4 Creating abundance through fostering connections and capabilities

The current system has over medicalised care and is focused on managing need (e.g. wait lists). This is not to say that we do not need more doctors and nurses and no one is arguing hospitals and specialised care are not important. But the bulk of care takes place in people's homes and in the community and it is people themselves and their families that do the lion's share of the caring. In the wake of the covid-19 pandemic, there was great investment in hospital ICUs, but although there was a lot of talk about valuing carers and other front-line workers, investment has not followed in the same way. It is by breaking down siloes, fostering participation and relationships that we can move from the current context of scarce resources (not enough doctors, not enough hospital beds, not enough funding, not enough time) to a context of greater abundance

through fostering connections and capabilities (of people being supported to flourish and therefore needing less medical care in the future, of people helping each other, of communities providing spaces and opportunities for their residents to keep well). This capability approach pioneered by Nobel-prize winning economist Amartya's Sen¹⁸ and described as a key principle of the new welfare state proposed by Hilary Cottam², is gaining traction internationally as an empowering approach to care – it shifts the way support is offered, i.e. a capability cannot be done to you. Each of us has to grow our capabilities, with support.

What the changemakers are showing is how, through enabling participation, through fostering relationships with and between everyone in the community, by partnering with people with lived experience, we ultimately can unlock a much richer set of resources (time, skills, relationships) to take care of ourselves and each other. Hilary Cottam, in her book *Radical Help*, talks about moving away from managing needs in a context of scarcity to creating abundance through activating community and relationships, creating capability rather than managing dependence, enabling people to flourish. Changemakers certainly demonstrate how this is done.

Creating abundance

Kwaito takes inspiration from Kate Raworth's Doughnut Economics - the idea is to meet the needs of all people within the needs of the planet. The neighbourhood entrepreneurship ('neighbourhood points') could be described as fostering a 'sharing economy', a rapidly growing movement that demonstrates how capacity can be created through making existing resources visible. A large part of the role of the Meeting Point coordinators is to identify the resources in the community and help connect them with those that may need them, and vice versa. For example, one of the employees who is also a person that lives with a disability loves to do the shopping and walk, so she delivers the weekly shop to an elderly woman with limited mobility and they both enjoy some time in each others' company, giving one a sense of purpose and reducing the other's isolation and loneliness.



Kwaito

Parma WelFare, through their Community Points offering light service to people in vulnerable situations, have similarly found a “collaborative-generative” phenomenon – one in which, through the act of coming together and establishing relationships, the creativity of the volunteers, facilitators and citizens is unleashed in finding solutions to all sorts of problems. The hospital clearly sees the value of this, as the co-located Hospital Hub allows for timely discharges and hence freeing up of hospital beds.

Foundry learned early on that they needed to increase the capacity of youth and young adults with mental health challenges to recognize their needs and navigate the accessing of appropriate resources. Creating this abundance was one of the most important outcomes of the developmental evaluation work.

Piosasco focuses on ‘regeneration’ by following what in Italy is called a ‘circular subsidiarity’ model, whereby the relationship between the different actors unlocks solutions to the various needs of the city’s residents. Whatever margin / revenue is generated through the programme is reinvested back into the project and therefore into the community. The project shifts the focus from people’s ‘problems’ to their personal resources and skills, by unlocking the capacity and experience of the person through an empowerment approach. Several of the beneficiaries have become volunteers.

aMIcittà uses a tool called the map of Todd as part of the recovery/ shared care plan notebook that the micro team works on with the beneficiary of the community personalised health budget. The map of Todd is a qualitative instrument to monitor and collect formal and informal social networks of people engaged in the project, usually used to evaluate the recovery process and interventions, but in aMIcittà it is also used for identifying strategies to improve people’s support networks with the co participation of person with lived experience.



aMIcittà workshop

Note of caution - it's about seeing each other as partners

There is a risk that some people might read this as a call to redirect funds from national health services or from specialized services onto the community or as a shifting of responsibilities from public authorities to the third sector or community-based organizations. This is not what ICC is about. It is about seeing each other as partners. **SOLENTRA** as an organization that provides highly specialized care feels very strongly about the need to invest in both specialized care and community care and to work together towards a common goal.

At **Ikambere** partnerships have been developed with hospitals so that they can refer women in need of reinforced social and therapeutic care to the association. IKAMBERE's health mediators also intervene in the infectious disease departments of these hospitals in order to conduct mediation activities and facilitate the dialogue between patients and health professionals, and conduct prevention actions. These close ties with the medical sector allows for the development of shared vision and goals with health professionals that interact with the beneficiaries on a regular basis and the team at Ikambere. Public institutions that are implicated in the improvement of health and the reduction of inequalities are also fully integrated in the process of improving the health and wellbeing of the community.

5

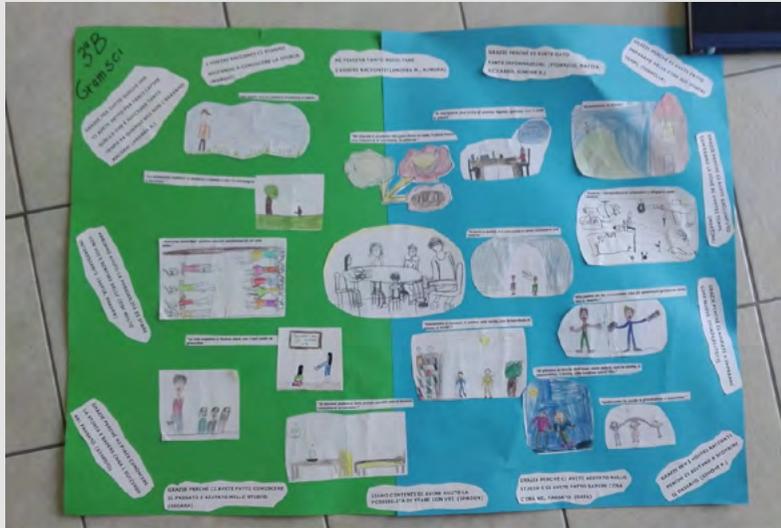
Outreach community events to raise awareness

Most changemakers acknowledge the importance of and invest in outreach activities and awareness campaigns to promote cultural change at a wider scale. They recognise schools, sports associations, cultural institutions as allies and often partner with them on a range of projects, creating local opportunities for inclusion and to raise awareness. Story telling is a useful tool.

Outreach

Vitaal Vechtdal – Start with a small gathering or event, with something that people recognize and identify with. Let people and the community participate, enjoy things, talk about it and spread the word. At the beginning, it may be disappointing and there may be less people than you expected involved. But stick with the frustration and it will grow. The movement / the big picture IS the collection of all the healthy living programmes that we put together with the community. The Board at some stage was saying: it's nice what you're doing, but what's the bigger picture. It's a healthier community!

aMIcittà and Piossasco – organize activities with schools including autobiographical narration, photo voice. This contributes to reducing stereotypes and opening a dialogue, making those involved feel safe in sharing their own stories which then opens up other opportunities for support.



Centro Paideia organizes training for people in the community at large e.g. accessibility at museums in Turin so that children with disabilities and their families are able to participate in cultural activities.

Piossasco organized a flash mob in front of the Elderly Care Facility, by engaging elderly guests of the facility, beneficiaries of the project and a large number of participants from local associations, students, families and teachers from local schools. The whole event helped to meet up together as a community and to build a stronger sense of identity.



Piossasco

6

What are the benefits?

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 groups¹⁹. Greater community participation can influence our health and wellbeing in many ways, including:

- Social networks and relationships (social capital) **reduce isolation** and **improve people’s resilience** in the face of adversity, essentially fostering solidarity and acting as a protective factor. They improve access to social support and to health and care services - creating abundance in the community.
- Strengthening **social cohesion** by nurturing a shared sense of identity, by bringing people together with a common vision, working towards a common (and positive) goal.
- **Civic engagement** or participation gives people a **sense of purpose and identity**. Health and wellbeing is understood as a shared responsibility and becomes a community project, improving quality of life. The vitality of civil society in a community significantly influences the ability to protect the health of citizens.

“The (Piosasco) project helped the community to get together and find a joint identity, to build a sense of community”

.....

Piosasco caring community

“What we are doing is re-establishing a network of ‘good’ neighbours in the city, like our parents may have had, but in a much more complex context, with a lot of mobility in the population, incoming and outgoing. The effect of Parma Welfare is helping people in difficult situations to connect with society, rebuilding cohesion. We haven’t gotten there yet, but we are increasing the levels of cohesion and trust”

.....

Parma Welfare

“the concept of social capital in its more complex form where relationships are used to protect health. The relations include between citizens and professionals, between professionals and between citizens.”

.....

Turin’s metrics



**New ways of
working**

*“Contrast
fragmentation: the
micro team works in a ‘collegial way’,
merging the various professions to give
more effective and integrated answers”*

.....

Pioissasco

Changemakers all work in collaborative and joined-up ways between professions and across sectors. Developing a workforce that can span health and social care boundaries requires transforming the organizational structures that influence how people work together as well as individual staff roles within those organizations. It also requires certain interaction and relational skills – the ability to listen to and recognize others, to observe, to ask and build alliances, bridging different professional languages and perspectives. These skills can be developed through regular practice and training, by creating setting and opportunities to engage in dialogue with others.

Some of the blended roles changemakers’ initiatives employ include:

- Community workers – these may have a background in social work, but not necessarily. They can be called animators, facilitators, dedicated activities’ manager, educators, operators, neighbourhood flatterers, community partners. They act as bridges between professionals and the community, they work to revitalize the dynamism of social groups. #Com.viso partnered with the University of Turin to study the topic of community development using an action- research approach as part of the project. An area of focus was the role of the community educator and the skills required to work in community development. A book is available in Italian upon request.



#Com.viso - animators

- Peer partners / experts by experience – these are people with lived experience of a particular condition/ disease/ situation of vulnerability that provide support to other people in similar circumstances as a peer.
- Health mediator provides individual personalized support to manage long term conditions.
- Cultural mediators / social interpreters both for language and cultural barriers.
- Professional integration counsellors to help address the social determinants of health.

Skills required for the new ways of working

The new ways of working described in this document require a range of relational skills. These are often character-based, with 'hard' skills from training complemented by 'soft' skills. These include:

- Able to provide practical as well as emotional support
- High emotional intelligence and self-awareness
- Good at establishing trust
- Active listening
- Facilitation skills
- Good communication skills
- Conflict resolution
- Patience – ability to 'stay with the frustration'
- Able to strike the right balance between professionalism and warmth/ being relatable



Outstanding challenges

Despite the immense creativity changemakers have to overcome all sorts of barriers, things are not always easy. Given changemakers are at different stage of development, one of the main issues they are currently grappling with is that of scalability. This has several different aspects: scaling up to different geographical locations, scaling up in terms of scope of services or target groups, scaling up in size (i.e. same service and target group, but increased demand). One of the main questions is how to remain true to the original principles whilst growing.

Transformation at a societal and system level does not happen overnight or even over political terms (3 – 5 years). It takes time and commitment. It requires careful planned transitions and investment in change management, protecting the work for long enough that it is able to grow strong enough roots. Unfortunately, long term funding is not often available for these types of initiatives and there are a myriad of legal and other barriers. These have been well recorded elsewhere. Not unlike start-ups in the private sector, there is a high risk of burnout due to the pressures and the uncertainty

around the sustainability. When we talk about funding, we tend to think about it in the context of our current systems, but releasing existing resources from what is not working or fit for purpose would enable investment in new forms of care. Philanthropy plays an important role, complementary to that of the government, acting as an investor for early stages of innovation and allowing more risk taking as they do not have the same constraints their government counterparts have. Philanthropy also plays a role in supporting research – maintaining a fruitful dialogue among theory and practice, between academic institutions and grassroot organizations and among different countries and systems that are facing similar challenges towards the goal of communities’ health and wellbeing, by supporting learning journeys – like the TransForm one. In the long term, it is the state that is the best placed to create the conditions for investment in these alternative models of care – to provide flexibility and funding to experiment with different ways of embodying the principles of integrated community care and to evaluate these to better understand what works and what does not.

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