2nd Transnational Conference on Integrated Community Care

"Towards People-Driven Care" Engaging and Empowering Individuals, Carers and Families through Integrated Community Care

A synthesis report of conference documents, discussions and learnings

Turin, Italy, 26-27 February 2019

TransForm Integrated Community Care

Transnational Forum on Integrated Community Care

Acknowledgements

This report serves as a synthesis of the key issues and themes, brought forward in all presentations and discussions during the Transform conference 'Towards People-Driven Care - Engaging and Empowering Individuals, Carers and Families through Integrated Community Care', held on the 26 and 27 February 2019 in Turin. The paper is not intended to report on all presentations in detail nor does it reflect the views or recommendations of the Forum as a whole or of its operating partners and funders.

We would like to acknowledge all speakers and participating delegates for their contributions during the conference (please see Appendix I for the participants list). For more information, background notes, presentations and video, see www.transform-integratedcommunitycare.com

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1. The TransForm Project

The Transnational Forum on Integrated Community Care – TransForm - is a joint initiative of seven partner Foundations from Europe and Canada coordinated by the Network of European Foundations (NEF) that aims to put the community at the centre of primary and integrated care. The TransForm partnership comprises: Compagnia di San Paolo (IT), "la Caixa" Foundation (ES), Robert Bosch Stiftung (DE), Fondation de France, Fund Dr. Daniël De Coninck, managed by the King Baudouin Foundation (BE) and Graham Boeckh Foundation (CA).

The ambition of the TransForm conferences is to discuss a complex issue of utmost importance: the capacity of local communities to deal with public health issues and care needs of community members over their course of life. The common aim is to explore the undoubted potential this new and diffuse concept of integrated community care presents. Even though integrated primary care is on the agenda in many countries, challenges in understanding how to design new ways of working together and supporting effective implementation remain.

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

Lessons learned from the first conference show that progressing towards ICC requires complex and adaptive system thinking. Community development is non-linear and must deal with unpredictability and emergent causality where the interacting agents, citizens, professionals and policy makers operate based on internal rules that cannot always be predicted. The actors adapt, interact and co-evolve across organisations and institutions and this demands new methods that incorporate how systems and communities come together as a whole.

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

2. TransForm Conference in Turin: the call for people-driven care

The TransForm conference explored different strategies and approaches aiming to engage and empower citizens, carers and families in the management of their own health and welfare in the context of their community. Please refer to the second input paper for more detailed information about the key ideas of people-driven care.

During the first session experience from the third sector, academia and experts-by-experience helped the delegates learn why the engagement and empowerment of people is a critical component for success in implementing ICC.

Francesco Profumo, President of Compagnia di San Paolo, emphasised during his welcome speech the important role that local communities play in dealing with public health issues and care needs of community members over their life course. However, there is a need to manage public health in new ways, in line with the increasing complexity of the health and care system. TransForm fosters the exchange of ideas, methods and practices at a transnational level, where participating foundations and their networks act as hubs of expertise. The time has come to make ICC reality. We need to understand which approaches and tools are needed at the micro and macro level to support participation, engagement and ownership.

The second conference took place at beautiful *Circolo dei Lettori* in Turin, Italy

Five overarching goals were set for the 2nd TransForm Conference:

1. Understand the key approaches to successful community participation in relation to implementing ICC, including the decision making processes that ease the creation and maintenance of new forms of alliances among stakeholders, taking into account new roles and power relations.
2. Illustrate how integrated community care better enables the active participation of individuals, carers and families in their health and wellbeing.
3. Demonstrate through evidence and practical experiences the positive impact that engaging and empowering people has on improving their quality of life, their care experiences and outcomes.
4. Illustrate how approaches to engagement and empowerment have been adopted in practice through established case examples as well as newly developed promising practices, including facilitated site visits to local innovations; and
5. Explore what competencies are needed by professionals and policy-makers to support, implement and deliver integrated community care and how to improve interdisciplinary training and learning.

During his introductory talk, **Nick Goodwin** (CEO of the International Foundation for Integrated Care) provided an overview of the key messages and themes emerging from the first conference on ICC held in Hamburg on 24-26 September 2018. Nick started by reminding delegates that ICC is a concept in development, but that a common understanding has emerged based on two key principles: first, that ICC is grounded in 'community health' – the ability to maintain, protect and improve the health of people in local communities through sustained community efforts; and second, that it must be supported by effective coordination of care delivered through inter-sectoral collaboration and co-productive partnerships.

The first conference also considered the key design features of ICC. Five core characteristics emerged as follows:

- *Assets-based* – engaging and empowering people as co-producers of their health (i.e. people-driven);
- *Place-based* – targeted at specific neighbourhoods or communities;
- *Home-based* – through focusing activities in non-institutional settings at the primary and community care level with the purpose of supporting people in their home environment;
- *Holistic* – by focusing on health and wellbeing
- *Equitable* – by tackling social exclusion and social isolation.

Nick emphasised the compelling case for ICC as a means to achieve better outcomes for people, particularly the most vulnerable and with complex needs. Whilst the scientific evidence-base is emergent, the case examples presented at the first conference demonstrated a range of positive impacts:

- in strengthening communities by targeting the social determinants of ill-health and reducing social exclusion;
- improving individual and community wellbeing;
- encouraging people's health seeking behaviour; and
- improving the sustainability of primary care through collaborative partnerships.

Finally, the overall conclusion that came out the first conference to enable effective implementation was stressed. ICC requires an assets-based approach to community development that is dynamic, unpredictable and non-linear. Implementation, therefore, requires adaptation to change over time as whole communities come together in an approach characterised by non-hierarchical processes, highly engaged communities, and distributed leadership. Nick concluded that 'active citizenship' was essential, including how individuals and families can become more engaged and empowered in their own health and care – the key topic for discussion during the second integrated community care conference of Turin.

2.1 Introducing the experts-by-experience

Four experts-by-experience offered delegates a reality check on what works and what does not work in terms of engaging and empowering people: **Carole Le Floch, Catherine Cerisey, Laura Tenuti** and **Micky Fierens**. Their powerful stories gave the audience food for thought and each of the expert-by-experience challenged delegates and policy makers to consider the lost opportunity of having patients and users training professionals and of having their voice truly heard in policy and practice.

Four questions were raised by the experts-by-experience panel:

1. *How can we increase the value of the expertise -by-experience as a qualification in the society?*
2. *How can experts-by-experience become a recognized and required part of healthcare and social services?*
3. *How can ICC become the trigger to change societies and improve people's self-management and independence?*
4. *What are you ready to do to accelerate the necessary cultural shift?*

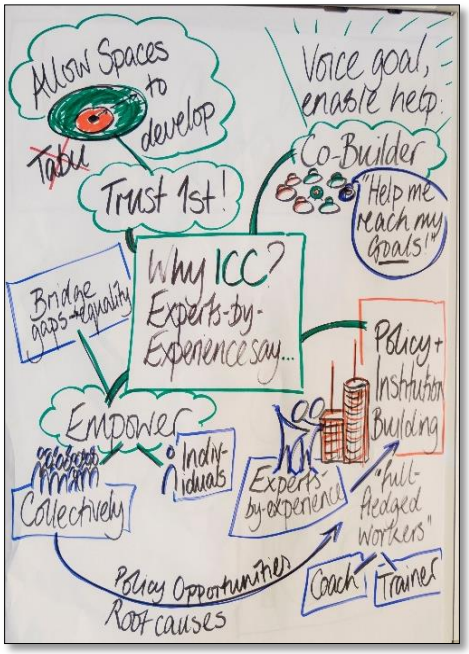

Figure 1 illustrating the concepts discussed by the experts-by-experience panel (by Natasha Walker)

2.2 Mobilising the community as an asset

People-driven care starts with recognition of people's needs and their strengths. It centres on what individuals can do, not their disabilities. Through a collective approach, people are engaged and empowered to take control of the factors that influence their health and wellbeing, including addressing social determinants of health.

Key note speaker **Don Redding** (Director of Policy and Partnerships for National Voices, UK) elaborated on what individuals, carers and families value in support of their health and wellbeing

and what works in terms of building people's strengths through community based approaches – what he termed 'mobilising the community as an asset'.

Using personal stories from people engaged with projects such as Creative Minds, "Walking for Health" and "Groundswell – out of homelessness", Don Redding demonstrated the value of activating people's inherent capacities. He referred to the *Realising Value Program*, where The Health Foundation together with Nesta has calculated the value of person-centred and community based approaches to health:

Resource	Possible savings (billion Euros per year)
Involving people in their care	5.6 to 13
Informal care givers	150
Volunteers	30.5
Voluntary and community sector	14

Don also drew participants' attention to a National Voices project which has studied what aspects of health and healthcare they value the most. He compared these values to what is being measured by health authorities today:

Elements being measured	What people value
Treatment outcomes	Health and wellbeing outcomes
Patient experience of services	Quality of life
Single service outputs	Cumulative impact of services and support
Individual care	Equity of care for groups and communities

Three ways for communities to support people-driven care were emphasized by Don: *shared decision making, personalised care planning* and *social prescribing.* When people and professionals **share decisions**, people are empowered to understand their options of care, and the risks, benefits and consequences of those options. Furthermore, they are supported to self-manage their long-term conditions. **Personalised care and support planning** is an evidence-based approach that helps to achieve **goal-oriented care**. Don asserted it involves a proactive, personalised conversation focusing on what matters to the person, not only their clinical needs, but their wider health and wellbeing. Lastly, **social prescribing** is made possible through *link workers* who co-design with the person a non-clinical prescription to improve health and wellbeing. Introducing link workers is an example of a strategy that may improve social cohesion. The idea is that the link workers or *bridge builders* connect the person asking for help with community resources, such as local activities, clubs, foodbanks or help with reducing debts. Don emphasized that although the funding comes from NHS England, the training and orientation of the workers should belong to the community to safeguard local values and needs are met.

2.3 Combating loneliness and building stronger communities through kindness

Interpersonal interactions and everyday relationships are at the heart of what is contributing to people's wellbeing. Building stronger communities therefore, implies exploring ideas around the importance of places and opportunities to connect. Key note contributor **Ben Thurman** (Policy and Development Officer at the Carnegie UK Trust) made a plea for enabling kinder communities. He reasoned why reasserting basic values, such as kindness, love and compassion, are so important for the wellbeing of individuals and communities.

The premise of the talk was that everyone *wants* to be kind, but that we need to remove the barriers that hinder us from building stronger communities. This involves targeting the major factors that get in the way for both individuals and communities to act humanistic. For example, funders' and policy makers' values (formal and organisational over the informal and individual), the modern definitions of professionalism and 'good' leadership (where everyday kindness and intuitive human interactions are crowded out). A lack of humanity may impinge trust in institutions tasked with providing care, and also making it difficult to support people to continue living at home as long as possible.

Figure 2 illustrating the concepts discussed by Ben Thurman (by Natasha Walker)

Carnegie UK Trust's research has explored why communities with similar socio-economic characteristics and population density differ in how they appear friendly and welcoming. So how do we create the conditions that allow kindness to grow organically both within institutions and outside? Ben Thurman gave three examples of kindness facilitators:

1) **Welcoming places** that are free to use, free from agenda and organisation, made from people and radiate warmness and hospitality.
2) **To spread informal kindness** in random meetings. Many people who are socially isolated tend to value informal interactions in e.g. the super market or with their hair dresser instead of organised activities.
3) Important **values of kindness** are to be kind to yourself, trust other people, take responsibility and question and act upon acts of unkindness.

Ben emphasised that we should foster *relational kindness* (allowing people to act naturally with each other) and remove the barriers to it:

Barriers to Kindness	Kindness enablers
• Personal risk (e.g. talking to homeless people or your neighbour). As a result, we tend to formalise our relationships; we volunteer for a charity or help organisations in fundraising because it feels safer and we can withdraw when we want to • Regulations introduced to manage risk in professional settings, e.g. risk assessments or turning low scale, informal initiatives into formal programs • Increased professionalism (instead of bringing a plate of soup to a neighbour, it is now provided by a formalised service) • Performance management	• Develop kindness promises • Break down hierarchical structures and give more autonomy for staff • Increase wages for front line staff • Trust staff to make meaningful connections with people • Protect time and create spaces for people to come together • Strong leadership and supportive corporate policies

The Scottish National Performance Framework sets the bar as to what to expect across all services: *"We are a society which treats all our people with kindness, dignity and compassion, respects the rule of law, and acts in an open and transparent way".* The statement, Ben concurred, reflects a strong political signal of willingness of moving towards more inclusive, empowered, resilient and safe communities in Scotland.

Key lessons learnt from the two introductory key note speeches
• The societal and economic value of care provided by volunteers and informal caregivers are significant and deserves more attention • What is measured gets done. However, we are not measuring what is important for people, such as wellbeing and quality of life. At the same time, measuring kindness at service level might lead to the same problem we are trying to solve: helping people act in ways that feels natural • Society has been overly focussed on professionalism and performance management. This has inadvertently resulted in complicating professionals' natural tendency to act with kindness • To facilitate the cultural change required, the benefits for professionals to act differently must be clear, but also, we need to break down hierarchical structures, increase wages for those in the frontline and grant staff more autonomy in making decisions on how they care for people

3. Demonstrating people-driven care in practice

In order to demonstrate how health and wellbeing initiatives have been working with design and delivery issues to successfully engage and empower individuals, delegates were invited to visit four local projects. Furthermore four international case studies were presented and discussed during the conference. These projects were chosen because they illustrate the impact of people-driven principles and services in improving individual's quality of life, care experience and resilience.

3.1 The Italian context

To help participants understand the context in which the local cases operate before visiting, **Cristiano Gori**, associate professor at the University of Trento, gave an insight into the Italian health and social system.

In Italy, most of the publicly funded care in the community is provided by the third sector. This has resulted in a multitude of innovative services emerging locally. However, the knowledge transfer from these projects to public services has proven difficult. Mainstreaming innovative practices has not yet been successful, mainly caused by unpredictable funding sources for innovative, bottom-up initiatives.

Traditionally, families contributed significantly in caring for their loved ones. Today, we see socio-demographic and cultural transformations. Families are changing, and people want to live more autonomous. Cristiano suggested that the increasing interest in health and social services provided outside the public realm may relate to people's dissatisfaction with public health services. Although funding of community care has improved in the last 20 years, it is still underfinanced compared to the acute and specialist care sectors.

Pointing at possible solutions, Cristiano encouraged increased collaboration between different stakeholders providing social, health and housing services and with the private and informal stakeholders.

3.2 Shared learnings from local promising practices

Participants learned from four local, promising cases how people can be engaged in co-designing health and empowered to increase their wellbeing. The four cases were: *Centro Paideia, Progetto Prisma, Aging better together: a project in Mirafiori Sud* and *the Working Group for Youth Policies* from Saluzzo. Please see the TransForm website for poster presentations of each of the projects.

Centro Paideia

Centro Paideia, the Centre for Children and Families in central Turin, provides rehabilitation, social activities and wellbeing for children, youth and the local community through a multi-disciplinary and integrated approach. More than 40% of clients are families with children with autism and other neuro-developmental needs.

The centre is socially designed and contributes to social cohesion by offering a mix of social, cultural, health, sport and recreational activities which is open for the local community.

Centro Paideia in numbers:

- 500 volunteers involved, 3000 families received social, educational and financial help so far
- Fundraising from voluntary contributions (benefactors who established the Centre, local families and local businesses) reach over €3m per year

Families involved in the care program, are in the driver seat when a care plan is developed. A coordinator safeguards the plan is personalized, based on the needs of the whole family and include multi-dimensional goals targeting all members of the family.

Key learnings from Centro Paideia

- The Family Centred Care methodology considers families as experts and partners in deciding on the child's wellbeing. The whole family's needs and goals determine care
- Connecting families in the same situation is a way of using community resources to provide support
- Allowing participants to pay what they are capable of and engaging participants in fundraising is an innovative approach to funding
- Socially designed – the centre is an open space offering activities for all community members
- A multidisciplinary team is engaged in the assessment of outcomes for each child, according to a multidimensional analysis and with systematic monitoring overtime.

Progetto Prisma

The Prisma project is above all a way of thinking - a philosophy embedded in the mind-set of all volunteers and professionals. Their focus is on increasing psychological wellbeing, social inclusion and changing the way people with disability are perceived. One of their main objectives is to help vulnerable persons use their resources, become their own problem solvers and even become trainers of professionals.

Key learnings from Progetto Prisma

- A common vision, philosophy and shared values among volunteers and professionals is a precondition for success as well as open access, low threshold and no prejudice
- Strong partnership with relevant associations and local authorities increases the project impact

- Change starts with focusing on psychological wellbeing, social inclusion and altering people's perceptions about persons with disability
- People can become their own problem solvers if only their capacities are acknowledged and supported
- The health and social system continues with services that are not customized to disabled's needs, which hinders spreading of the "everyone can" approach

Project results include:

- 5000 people are involved or reached so far
- A horizontal collaboration between public social service and more than 20 associations
- Evaluation shows increased QoL in target population and improved cultural sensitivity among health professionals

Aging better together: a project in Mirafiori Sud

Earlier, the Mirafiori Sud district had wide immigration from all over Italy, thanks to Mirafiori serving as the headquarters of FIAT. Now, the car industry has shrinked, the population in Mirafiori Sud is aging and many elderly lives alone. The *Aging better together* project aims to stimulate active participation in local activities and strengthening informal neighbourhood networking. Social workers help coordinate the activities, but many are also run by elderly volunteers alone.

Participants must be able to attend activities autonomously, as assistance resources are scarce. Although the main purpose of the project is not to provide health care, the participants look after each other, and when needed, the centre helps people connecting with home care or mental health services.

Key outcomes of the *Aging better together* project:

- Countering stereotypes about elderly in deprived areas
- Improving social cohesion
- Participation and peer-to-peer learning
- Reducing social isolation by connecting elderly living alone
- Independent living
- Learning new skills

Key learnings from Aging better together: a project in Mirafiori Sud

- Example of sociodemographic integration, following a period of social upheaval after reduction of the FIAT activities
- Example of how loneliness and independent living can be targeted by connecting isolated individuals through accessible activities
- Co-creation of activities (e.g. through local world cafés) stimulates active participation, strengthens informal neighbourhood networks and fights loneliness
- Example of bottom-up, primary prevention initiative, targeting "softer" measures like social isolation, quality of life and wellbeing, which might not get as much recognition as it deserves by local authorities and policy makers

Working Group for youth policies in Saluzzo

The Working Group for youth policies from the Saluzzo region aims to integrate diverse organizations and services targeting residents in Saluzzo between 14 and 20 years old. Their mission is to help achieve social inclusion of youth at risk outside traditional institutional care.

They reach out to adolescents in arenas where they hang out to learn together with them how they can be empowered to take part in the life of the community. The initiative focuses on early detection of drug abuse and school drop-out, fighting this with involving kids in arranging events on their premises.

Trusting youth with responsibility
To foster youths' feelings of mastery, the Working Group encourages youth to organize their events alone with only minor guidance from the project group. This has proven successful and more than 3000 people (not only youth) have participated in each of the **"wake up events",** strengthening social cohesion across generations in Saluzzo.

Key learnings from the Working Group for Youth Policies

- To get youth on board, you must be visible in the streets were they spend their spare time
- Engaging adolescents, means playing by their rules. Adults' and youths' perceptions about youths' preferences, resources and needs are not the same
- This is a successful example of how previous participants become role models for the next generation
- Sometimes, creating new services is not necessary. Instead, focusing on improving communication and relationships across generations is more effective
- Trusting youth with responsibility fosters their feelings of mastery
- Developing a common objective, culture and language between actors from the medical and social sectors is difficult
- Evaluation must be planned from the beginning, otherwise showing the impact of the project on the community is not possible

Debriefing from site visits

Following the site visits, participants broke into groups to debrief on their impressions from the visits. In particular, they discussed what aspects of the cases that worked well, what could have worked better and what was considered relevant to bring back to their own practice.

What works?	• Scrutinize individual and/or population needs and use this information as a foundation for activities • Connect people, fight loneliness, build social skills and promote neighbourhood networking through informal activities • Acknowledge people's capacities, provide support for individuals in becoming problem solvers, peers and role models • Remuneration is powerful in terms of power dynamics, motivation and sustainability
What could work better?	• Most projects are run in parallel with the public health and social care system, where traditional care and cure perspectives remain. It is a challenge to affect system level way of working • Evaluation is often missing and must be planned before project start up
What participants learned	• Innovative funding practices are sensitive to individual economy. Encourage people to pay what they can and support those who cannot • Regard previous participants as a resource

	• Meet regularly with all stakeholders to consolidate emerging or neglected needs and review demands for funding • Integrating evaluation as part of the project mission will help generalize conclusions, inform scale up and transferability

3.3 Successful international case studies

Adding to the demonstration of local experiences of people-driven care, four international cases drew participants' attention to successful policy initiatives to support community development and social cohesion. Please visit the TransForm website for poster presentations of each of the international cases. Following the presentation of each international case, a facilitated *World Café* was arranged where delegates discussed the strengths, impacts, challenges and replicability of each example. Key learnings from the discussions are highlighted at the end of each presentation.

Scotland's integrated health and wellbeing boards

Geoff Huggins, Director of Health and Social Care Integration at the Scottish Government, presented the Scottish story of moving towards integrated health and wellbeing boards by developing policy across sectors and with the community.

"We have universal services, but how those services are used is not universal", Geoff Huggins

In Scotland, there is a 300% variation as to whether an elderly will spend a day in hospital over the year and a 100% variation as to whether you will be hospitalized during the last six months of your life. 2% of population uses 50% of hospital resources. 60% are not using any services at all. These variations are related to different service structures, demographics, demand and supply and local public and clinical behaviour. Essentially, there are different systems being run across the country when it should be one.

In terms of accessibility, there is a remarkable demand for rethinking how the systems are designed to meet the needs of the high-spending population. These changes require strong and consistent political, clinical and professional leadership. Therefore, a key ingredient of the Scottish reform is the legislation of a single budget and commissioner for health and social care and establishment of 31 Integration Authorities (IAs), which are responsible for planning, commission and reporting of services. This is an example of successful top-down governance where health boards and local authorities have to work together, which in the end, leads to empowerment of communities.

Geoff Huggin's ICC indicators wish list:

- To what extent people are enabled to look after and improve their own health and wellbeing and live independently at home with good health for longer
- People's experiences of the services they receive
- If health and social care services contribute to reducing health inequalities
- If informal carers are supported to reduce any negative impact of their caring role on their own health and wellbeing
- If people who work in health and social care services feel engaged with the work they do and are supported to continuously improve the care they provide

Key learnings on impact, challenges and replication – The Scottish story

Strengths/impact

- Integration of health and social care with a common budget to enforce joint responsibility and accountability
- Letting local authorities decide how funding is spent and establish a common value-based outcomes framework everyone reports in to
- Focus on higher level outcomes that matter for people rather than performance targets

Challenges

- Building community leadership
- Different working and management cultures affects to which extent local authorities develop new partnerships to meet local needs and improve outcomes
- Local authorities are still not responsive enough in terms of citizen & community involvement
- Transferring budgets from specialist care to primary care; keep costs manageable

Important factors for replication

- Be aware that creating new roles to enable ICC takes time. It took Scotland 10 years of negotiations to change the legal frameworks to allow for new roles or using funding flexibly. Dialogue is key to overcome this barrier
- A core piece of infrastructure is the team of 50 people tasked with data analysis. You need to map how systems are operating and use data to produce change - and remove the practices that do not work

CoFoR project (Recovery Training Centre), Marseille, France

Aurélie Tinland, psychiatrist and part of the Movement and Action for Recovery in Health, Social and Citizenship team, presented the CoFoR project. CoFoR, aims to enable people with mental health issues to become experts in their own care and develop the skills and confidence to manage their own recovery journey.

"People who have come out of it have so much to teach others", Aurélie Tinland

The model is all about life literacy – to teach people with psychiatric disorders to teach others with similar problems about recovery and living a happy life. It enables people with mental health issues to become experts in their own care and develop the skills and confidence to manage their own recovery journey.

Being philosophically underpinned by a participatory approach, only 10% of the teachers have professional background, the rest are peers and ex-students. The project has a flat structure in that professionals and peers earn the same and everyone's voice counts equal.

One-year results

- 89 students registered, 49 students graduated
- Student satisfaction rate: 7.9 on a scale from 1 to 9
- Self-stigmatization rate significantly reduced post course

Key learnings on impact, challenges and replication – the CoFoR project

Strengths/impact

- Mixed group of participants (age, gender, experience) have synergetic effects on learning and recovery
- Patients become students, which help reduce stigmatisation and regain self-confidence
- Common values include care, respect, cultural capital and life literacy
- Dynamic and life-relevant curricula co-constructed with the students to support mastering and self-sufficiency
- Bonus payed to every student completing the course

Challenges

- Keeping up students' momentum during and after training
- Financial insecurity and lack of official recognition
- Recruitment and risk of facilitator burnout due to the day-to-day load of working with empowering people who face mental disease
- Small teams, where power-imbalance might cause disturbance in group dynamics

Important factors for replication

- Having a favourable environment with interested beneficiaries and policy makers
- A location which supports recruitment of facilitators

The Habitat-Microarea Program, Trieste, Italy

Sari Massiotta, from the local health authority of Trieste, presented the Habitat-Microarea Program, a social, health and housing joint program aiming at creating effective integration between policies and sectors and to positively influence life contexts by actively involving the local community. The objective of the program is to improve quality of life and wellbeing through promoting social cohesion, health monitoring and prevention and building stronger communities.

The fundamental ingredient in the Habitat-Microarea Program is the person-centred approach which involves users and families in planning, providing and evaluating services. This is not a targeted intervention or a replacement strategy for existing services. Instead, multi-disciplinary teams serve as to integrate existing social and health services in a life-course approach by matching at the micro level, the demands for services with the available public and private resources.

The whole community is engaged in the program design, and needs, challenges, problems and resources are uncovered together to create new alliances for co-production and enabling active citizenship.

Results after nine years

- Significant decrease in urgent hospitalisation related to psychosis, acute respiratory infections and cardiovascular pathology
- Decrease in multiple hospitalisations for women
- Signs of increased social capital and support mechanisms for the most vulnerable
- People are more involved in taking care of each other

Key learnings on impact, challenges and replication – the Habitat-Microarea Program

Strengths/impact

- Asset-based, bottom-up and learning-by-doing approach. Based on knowledge and negotiation among all stakeholders in the local community
- Inter-institutional partnership established through formal agreements
- Approach proven effective in enhancing social capital, people's perceived wellbeing, feelings of commitment and engagement
- 20 years of experience thanks to financial guarantees

Challenge

- To keep professionals in the community rather than in specialist care
- Unstable leadership in healthcare institutions
- Difficult to deal with social determinants of health

Important factors for replication

- Example of how it is possible to evaluate at micro level
- The program is dependent on supporting regulations, laws and financial flexibility
- New ways of working necessary during start-up phase, professionals were out of their comfort zone when knocking on doors to activate informal resources. Important not to define or limit professionals' roles by competencies when they accept innovative solutions
- Although focusing on the population, do not forget to keep attention to most vulnerable

Community Health Centre 'Botermarkt', Gent, Belgium

Veerle Vyncke, Flemish association of Community Health Centres (CHCs), presented the community health centre 'Botermarkt' in Ledeberg. The 11 CHCs in Gent aim to ensure access to comprehensive primary care for people living in Gent.

Every community health centre has a multi-professional team consisting of minimum 3 disciplines, a GP, nurse and social worker. When a person with complex problems contacts a centre, an interdisciplinary meeting is held to identify relevant care needs. Their way of working is to focus on learning from individual patient stories and how they can target their services based on people's social characteristics, such as were they live, their working conditions and if they feel lonely. A care plan is developed together with the person based on their life-goals. As an example of how the community health centres work person-centred and engage people in developing services, Veerle referred to the *Multiloog.*

The *Multiloog*

A multiloog is a dialogue between many people. The dialogue is led by a psychologist who talks to the local population and experts-by-experience of mental health issues. The goal is to co-produce and improve accessibility of services targeting persons with psychological vulnerability and to create new, warm meeting places.

Key learnings on impact, challenges and replication – the CHC 'Botermarkt', Gent

Strengths/impact

- Example of how social cohesion can be improved by placing the community (not only individuals) at the agenda of primary care
- Needs-based capitation financing and salary-based employment (no internal competition or hierarchy)
- The centre is connected to the larger community through stakeholder and care provider mobilisation. Staff at the centre have a long track record of being present in the community which enables them to take social determinants into account
- The health promoters, part-time paid by the city of Gent, are key through their population-oriented focus on prevention
- Care plans are goal-oriented and co-created between patients and the inter-professional team

Challenges

- Engaging people in the development of activities
- No formal evaluation. Difficult to establish quantitative goals at the population/public health level (population is very mobile: 20% move on a yearly basis)
- The CHCs target only 4% of the Belgian population
- How to handle patients that never show up? (> outreach activities)

Important factors for replication

- Involvement of stakeholders and creating good relations with local authorities
- Support from city council and the social director in every district
- Community care council responsible for coordination of and support for primary care networks in the "Primary Care Zone" Gent

4. Preparing the workforce to be a partner in integrated community care

Developing an integrated care system means we must look at professional roles and responsibilities differently than we do today.

Anne Wojtak, Executive Lead for Transformation at the Toronto Central Local Health Integration Network, suggested which competencies are necessary for professionals and decision-makers to be able to work in a new environment where communities are supported in strengthening themselves.

Professionals, patients and informal carers are part of the same team

Person-centred and people-driven approaches require new visions to inspire professionals in working differently. In Canada, 80% of care in people's homes is provided by family. Recognizing their great value, the inter-professional team must expand from a team of healthcare professionals, to a team which includes the patient, his or her family and informal carers. These new ways of working involve co-designing a multilevel care plan, based on individual preferences and life goals. Ideally, the plan is supported by a combination of clinical expertise and lived experience. To succeed in this, new frameworks are required to support reflective learning among professionals, patients and carers. This also implies training of professionals in how they can efficiently collaborate with patients and caregivers to reduce everyone's stress levels and promote their self-efficacy.

Anne suggested that the quadruple aim; enhancing patient experience, improving population health, reducing costs and improving the work life of health care providers, should preferably be extended with a fifth aim, i.e. including the health and wellbeing of unpaid family caregivers.

Shared leadership
In terms of power and influence, leaders must change from leading organisations to leading whole systems where hierarchical power structures are not effective. Governance should be shared and place-based. Anne introduced 'leaderful' teams as teams that make decisions, having leaders guiding from behind the scene.

Take home messages on workforce development:

- The healthcare workforce must be trained in people-driven care approaches which imply including patients and informal carers as part of the inter-professional team
- New competencies are necessary to build care around individual life-goals and preferences
- To create high functioning teams, workers must be allowed to step out of their traditional roles. The answers no longer reside with the clinical experts, they are co-created together with patients and his or her family
- The ultimate goal is peer to peer training, where professionals stand at the side-line as coaches. To get there, we must provide families with confidence of what they are capable of

5. How can policy enable people-driven care?

In this session, participants debated with policy makers in Speakers' Corners the tactics and strategies for creating policy that enables people-driven care. The four policy makers were:

- **Augusto Ferrari**, counsellor from the Piemonte region (Italy)
- **Nathalie Noël**, Deputy Director of Health at the Cabinet of the Brussels Minister for Economy, Labour, Vocational Training and Health (Belgium)
- **Claude Allard**, Associate Deputy Minister Health Services and Francophone Affairs Department of Health Government of New-Brunswick (Canada)
- **Laurent El Ghozi**, president of Élus, Santé Publique and Territoires (France)

Two main themes arose from the discussions:

1. **Strengthen primary care and address social determinants of health**
   - Support the transition to new models of primary care by redirecting funds out of hospitals and into health and social care in the communities
   - Create social policy measures to reduce poverty, inequalities and address social determinants of health
   - Consider public-private partnerships in working with public health and prevention
2. **Unlock community and individual resources and secure sustainable funding**
   - Communities are the protagonists. Policy makers should facilitate achievements of their objectives, e.g. by supporting local grassroots organisations from different levels and sectors in joining forces
   - Initiate local workshops where citizens can meet with their local elected politicians and present focus areas to be included on the political agenda
   - Integrate social and health care and establish social and health funds
   - Local policy makers have an important role in convincing the regional or national level to implement innovations on health and participation

6. Reflections and take-home messages

At the closing of the conference, participants brought attention to the need for adjustment when thinking of professional roles. They particularly recognized the idea of allowing space for more kindness and for healthcare professionals to act more personally and natural when at work, as a relevant issue needing further exploration. A poll among the participants asking what they considered as to hinder transformation of health and care services the most, showed that **fear of the unknown** and **lack of trust** are the main challenges we must deal with to move forward. These reflections become even more relevant when revisiting the experts-by-experience's introductory questions.

Jan De Maeseneer (Department of Public Health and Primary Care, Gent University) and **Jodeme Goldhar** (the Change Foundation), representing the TransForm Advisory Group, helped the audience consolidate the conference contributions and suggested where we need to direct our resources next.

Jan commented that fear and lack of trust is highly significant because it reflects what is going on in the society in general. Answering the experts-by-experience's question of how their knowledge can be recognized in healthcare and society, Jan explained people in general feel they are not taken seriously. They feel dispirited and sometimes humiliated. We all share this uncertainty. The good news is that every individual, but also a well-performing primary care system, can contribute to social cohesion and the trusting relationships that is needed to develop resilient communities. As part of a normalisation process, we must build resilient communities where stigmatisation disappears and remind our politicians that social cohesion is an essential condition for building societal projects.

Jodeme asserted that TransForm has bold aspirations. She emphasized that we all have a valuable contribution, regardless of lens towards making ICC a reality. For example, the person welcoming people in the reception is representative of the whole system's shared sense of purpose and plays a key part in reaching the organisation's goals.

Further summoning the learnings from Jan and Jodeme, presenters, case visits, experts-by-experience and group discussions, a list of seven high-level themes emerged.

Key principles and take-home messages of people-driven care

1. **Shift from old to new power**
   The old power, where few people hold power and the rest listens, belongs to history. The command and control style of leadership is not useful anymore. New power means change is informed by everyone – we are mutually held accountable. Everyone have valuable contributions and should be held accountable. New power is informed by a different value system, a system developed from patient-*oriented* care, via patient-*centric* care to the emergence of people-*driven* care. Being in a position of power today, means you need to listen, learn to adapt and recognized that the process is what matters, and no system can be standardized. *"Patient-driven care is about having patients and experts by experience **around** the table not at the centre" (expert-by-experience)*
2. **Dealing with complexity and accepting variability**
   ICC implies dealing with questions that are at the crossroads between sectors and disciplines; between healthcare, public health, social care and between formal and informal support. Healthcare is a complex adaptive system in that it is dynamic and cannot be standardised. To navigate, variability must be accepted and change guided by values and high-level goals. What happens in one population is different from another. Different communities mean different

needs, and to satisfy those needs, the only way is to shift to co-design and co-production. Enforcing standardisation hinders realisation of potential population-based models of care. As levers of policies, leaders must embrace complexity and variability in the pursuit of high-level goals.

3. **Convening and coordination**
   Asset-based and place-based approaches involve establishing co-productive partnerships between community services, third sector organisations and the people, where citizens play an active part in the cycles of planning, implementing and evaluation of services. Coordination must be directed in a way that links people and communities to what is important to them – not just a set of activities and services that are available. Leaders' new role in this system is to coordinate and convene these interactions without knowing where they will end up. *"It is important to translate individual life-stories into useful action all the way up to policy" (expert-by-experience)*
4. **Co-design and co-production**
   A people-driven approach connects individuals and families to community resources and increase upstream participation. It strengthens social capital, community cohesion and resilience. Co-production requires new research questions to be posted and new interventions to find the answers. Professional experts need to take the position as guides and coaches on the side; from providing information and solutions to providing input. We can no longer shame and blame but learn together by listening to lived experiences to help inform new policies, new research questions, new ways to evaluate and design models of care and ultimately, build communities that thrive.
5. **Recognizing civic knowledge as part of the solution**
   People engagement implies a shift from a supply-driven care system towards people-driven and goal-oriented care. Key to this transformation is reframing healthcare professionals' roles and approaches so that they can help people living better lives with their conditions. It also involves legitimatisation of civic knowledge and allowing professionals to act in kindness, from one human to another.
6. **Equity – a shared sense of consciousness**
   Moving from an ego-centred perspective to an eco-centred perspective means we must always consider the broader system and recognize the possibility of abundance for all. This philosophy contrasts with asking what you have or not have from a professional or citizen lens. Instead, we must ask: what kind of life do people want to live and what do they need to live that life?
   Self-supported people are not patients, they are experts-by-experience, active citizens, students, partners, peers and problem solvers. Self-supported people are a community resource and a normalisation process is necessary to fight stigma and see all people as equal contributors.
7. **Recognising and supporting informal carers**
   Voluntary involvement without institutional, vocational nor financial bindings plays a significant, but unrecognised role in today's health systems. However, we know little about what they can do, how they want to be engaged and how we can operationalize and support their efforts. Professionals will also need training in collaboration with informal care networks and how to reconcile lay and professional knowledge.

7. How to build stronger communities through ICC

Whilst these seven points are set as the overarching principles guiding the transformation towards people-driven care, established institutional, organizational and professional paradigms still dominates participatory care-integration efforts. 'Individuals', 'citizens', 'people' and 'experts-by-experience' tend to remain marginalized within the dominant frameworks that shape our thinking about ICC. Most of the time, the 'participants' are still positioned as passive recipients of professional or political efforts of integration. There is a need to understand how to enable active

participation and empowerment of communities in decision-making, including an examination of responding to different cultural contexts and the building of social capital.
The next TransForm conference, hosted by the Graham Boeckh Foundation in Vancouver, 2-4 October 2019, will study how we can build strong communities through ICC. The conference has four main objectives:

1. Understand the principles and approaches of decision making processes and governance that facilitate the creation and maintenance of new forms of alliances and successful community participation in relation to implementing ICC
2. Demonstrate through evidence and practical experiences the positive impact that ICC approaches has on improving people's health and wellbeing, including addressing social determinants of health and the barriers to implementing it
3. Explore how to mobilise policy-makers and community leaders to take the lead towards system transformation
4. Demonstrate how evaluation and research can support the design and deployment of ICC

8. Further readings

Miller, John H., and Scott E. Page. *Complex adaptive systems : an introduction to computational models of social life*. 2007. Princeton University Press. ISBN 9781400835522. OCLC 760073369.

NHS' publication on Universal Personalised Care, 2019.

South et al. An evidence-based framework on community-centred approaches for health: England, UK, 2017.

The Carnegie UK Trust:

Conversations with young people about kindness, 2019.

Quantifying kindness, public engagement and place, 2018.

Emotions and human relationships: the blind spot in public policy, 2018.

The Place of Kindness, 2017.

Evans JM, Daub S, Goldhar J, Wojtak A, Purbhoo D. Leading Integrated Health and Social Care Systems: Perspectives from Research and Practice. 2016.

Change Foundation: www.changefoundation.ca/category/family-caregivers/

Centre for Interprofessional Education: www.IPE.utoronto.ca

Figure 3 - Energising coffee break at Circolo dei Lettori, Turin

Appendix I – List of participants

Name	Organisation	Country
Claude Allard	Government of New-Brunswick, Department of Health	Canada
Corinne Bebin	City of Versailles	France
Loïc Biot	Ville de Grenoble - Direction santé publique et environnementale	France
Marie-Aline Bloch	Ecole des Hautes Etudes en Santé Publique	France
Angélique Buccella	Agence pour une Vie de Qualité	Belgium
Cinzia Canali	Fondazione Emanuela Zancan	Italy
Valeria Cappellato	Compagnia di San Paolo	Italy
Alice Casagrande	Fédération des Etablissements Hospitaliers & d'Aide à la Personne Privés Non Lucratifs (FEHAP)	France
Marion Caspers-Merk	Robert Bosch Stiftung	Germany
Céline Engel	Cofor	France
Catherine Cerisey	Associons nos savoirs	France
Alexandre Chudant	Fédération des Acteurs de la Solidarité / TAPAJ France	France
Victoria Conconi	Robert L. Conconi Foundation	Canada
Karin Cormann	Ministerium der Deutschsprachigen Gemeinschaft	Belgium
Yves Dario	King Baudouin Foundation	Belgium
Jan De Maeseneer	Department of Family Medicine and Primary Health Care Ghent University	Belgium
Hilde De Nutte	Zorgnet-Icuro Care Network Flanders	Belgium
Antoni Dedeu	International Foundation for Integrated Care (IFIC)	United Kingdom

Martine Delfosse	Wit-Gele Kruis West-Vlaanderen (Home nursing)	Belgium
Ann Demeulemeester	Familiehulp	Belgium
Anneke Denecker	King Baudouin Foundation	Belgium
Hélène Dispas	Fédération des Maisons Médicales (Community Health Centers)	Belgium
Silvia Dorato	Compagnia di San Paolo	Italy
Nieves Ehrenberg	International Foundation for Integrated Care (IFIC)	United Kingdom
Laurent El Ghozi	Elus, Santé publique et Territoires	France
Oriana Elia	Comune di Torino, Social Services Division	Italy
Raffaella Ferrantino	MCP&Partners	Italy
Augusto Ferrari	Piedmont Regional Government	Italy
Céline Feuillat	Asbl Aidants Proches	Belgium
Micky Fierens	Fédération francophone indépendante d'associations de patients et de proches	Belgium
Gaëlle Fonteyne	Promo Santé & Médecine Génerale (PSMG)	Belgium
Isabelle Gamot	Ville de Grenoble - Direction santé publique et environnementale	France
Agustina Gancia	Centre of Excellence on Partnership with Patients and the Public	Canada
Luc Ginot	Agence régionale de santé (ARS) Ile-de-France	France
Federica Giuliani	Municipality of Turin, Social Services Division	Italy
Jodeme Goldhar	The Change Foundation	Canada
Nick Goodwin	International Foundation for Integrated Care (IFIC)	United Kingdom
Cristiano Gori	Dipartimento di Sociologia e Ricerca Sociale – University of Trento	Italy
Stephanie Häfele	Robert Bosch Stiftung	Germany
Anita Hausen	Catholic University of Applied Science Munich	Germany
Mélanie Hubault	Fondation de France	France
Geoff Huggins	Health and Social Care Integration at the Scottish Government	United Kingdom
Danielle Kemmer	Graham Boeckh Foundation	Canada
Christine Kersting	University Witten/Herdecke	Germany

Susanne Kiepke-Ziemes	Caritasverband für die Region Kempen-Viersen.e.V.	Germany
Sandra Korge	Björn Schulz Stiftung	Germany
Sophie Lasserre	Fondation de France	France
Carole Le Floch	Formatrice/intervenante paire dans les écoles du travail social	France
Dominique Lemaistre	Fondation de France	France
Cecilia Marchisio	University of Turin, Centro studi per i diritti e la vita indipendente	Italy
Luisa Marino	Network of European Foundations (NEF)	Belgium
Sari Massiotta	Trieste local Health Authority	Italy
Roberta Molinar	APS CentroX100/Fondazione Mirafiori	Italy
Paolo Nerino Caraccio	Consorzio Monviso Solidale & Cooperativa Proposta 80	Italy
Nathalie Noël	Cabinet of the Brussels Minister for Health	Belgium
Karine Pouchain-Grepinet	Fondation de France	France
Francesco Profumo	Compagnia di San Paolo	Italy
Antonella Rai	Municipality of Trieste	Italy
Salvatore Rao	Associazione La Bottega del Possibile	Italy
Anita Reboldi	Compagnia di San Paolo	Italy
Don Redding	National Voices	United Kingdom
Roy Remmen	University of Antwerp	Belgium
Jesse Renard	Carevolution / Partena Promeris	Belgium
Franco Ripa	Regione Piemonte, Health Division	Italy
Thomas Sannié	Association française des hémophiles	France
Wilfried Schnepp	Witten/Herdecke University	Germany
Veronika Schönhofer-Nellessen	Servicestelle Hospiz für die Städteregion Aachen	Germany
Ava-Dayna Sefa	Generation Capital	Canada
Nathalie Senecal	Fondation de France	France
Fabrizio Serra	Fondazione Paideia onlus / Centro Paideia	Italy

Reinilde Seuntjes	General Practitioner	Belgium
Marzia Sica	Compagnia di San Paolo	Italy
Sanja Simic	Robert L. Conconi Foundation	Canada
Monica Sorensen	International Foundation for Integrated Care (IFIC)	United Kingdom
Laura Tenuti	Centro Salute Mentale di Trento	Italy
Livio Tesio	Regione Piemonte	Italy
Ben Thurman	Carnegie UK Trust	United Kingdom
Aurélie Tinland	Marseille Public Hospital & Aix Marseille University	France
Yvan Tourjansky	Union Régionale des Professionnels de Santé Masseurs-Kinésithérapeutes d'Île-de-France	France
Thérèse Van Durme	Université catholique de Louvain, Institute of Health and Society	Belgium
Hendrik Van Gansbeke	Wit-Gele Kruis van Vlaanderen (Home nursing)	Belgium
Tinne Vandensande	King Baudouin Foundation	Belgium
Tom Verhaeghe	Federal Ministry of Public Health	Belgium
Caroline Verlinde	Cabinet of the Flemish Minister of Health, Welfare and Family	Belgium
Emily Verté	Free University of Brussels & University of Antwerp	Belgium
Manuela Völkel	Philosophisch.theologische Hochschule Vallendar	Germany
Veerle Vyncke	Flemish Association of Community Health Centers	Belgium
Natasha Walker	International Facilitation and Communication	Germany
Anne Wojtak	Adaptive Strategy Partners	Canada
Ursula Wolf	University Hospital Halle (Saale)	Germany