1st Transnational Conference on Integrated Community Care

'Making the case for Integrated Community Care'

A synthesis report of conference documents, discussions and learnings

Hamburg, Germany, 24-26 September 2018

TransForm Integrated Community Care

Transnational Forum on Integrated Community Care

Acknowledgements

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We would like to acknowledge all speakers and participating delegates for their contributions during the conference (please see Appendix I for the participants list).

Disclaimer

This paper was developed by the Transnational Forum for Integrated Community Care. TransForm is a joint initiative of seven Foundations in and beyond Europe that aims to put the community at the centre of primary and integrated care. The TransForm partnership is funded and hosted by the Network of European Foundations and 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 International Foundation for Integrated Care provides content and management support to the project.

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Contents

1. Introduction 4
1.1 TransForm Project 4
2. 1st TransForm Conference in Hamburg 4
2.1 Making the case for Integrated Community Care (ICC) 4
2.2 Engaging people and communities as co-producers of health 5
2.3 Asset-based community development 5
3. Design and impact of ICC 9
3.1 Community Health Center Port Hohenstein (Reutlingen, DE) 9
3.2 Live well, feel better ("la Caixa" Foundation, ES) 9
3.3 Experiences from local example projects of ICC 10
3.4 Summary of experiences from the local projects 15
4. Implementation of ICC 16
4.1 Presentation of successful cases of ICC: Jigsaw, Quartiers Solidaires and Millom 16
5. Policy development 18
5.1 Summary of Speakers' Corners session 19
5.2 How can we take ICC forward? 20
5.3 From communities to families and individuals 21
6. References 22
Appendix I – List of participants 23

1. Introduction

1.1 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.

Gerrit Rauws of the King Baudouin Foundation has outlined, on behalf of the partner Foundations, the ambition of TransForm 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. How can we support communities to develop successful models where people's engagement is fostered through co-production of care?

The purpose of TransForm is to explore the undoubted potential this new and diffuse concept of integrated community care presents. Even though primary care and integrated care are on the agenda in many countries, challenges in understanding how to design new ways of working and supporting the effective implementation of integrated community care in practice still remains.

In Integrated Community Care (ICC) people and communities are recognised as co-producers of care. The project will include a mapping of promising practices in a series of conferences and visits in Europe and beyond, serving as a support for knowledge generation and sharing that hopefully will bring about change in national health policy agendas. The TransForm initiative aims to inspire policy-makers and practitioners to mobilise change and strengthen the capacity of local communities to meet the health needs of community members, with a special focus on the most marginalised groups of the society.

2. 1st TransForm Conference in Hamburg

The first conference in Hamburg, "Making the case for integrated community care" is the first of a series of four transnational conferences. It aimed to develop a common understanding of the meaning of integrated community care and demonstrate through evidence the positive impact integrated community care can have on tackling inequalities, improving care experiences and care outcomes. This included the exploration of essential design elements in the provision of integrated community care that make the approach successful.

Each conference will build upon the previous ones, creating a crescendo of learnings on integrated community care.

2.1 Making the case for Integrated Community Care (ICC)

During his introductory talk, Nick Goodwin from International Foundation for Integrated Care (IFIC) presented five goals for the first Transform Conference.

Five key objectives for the first TransForm Conference
1. Develop a common understanding of the meaning of integrated community care 2. Demonstrate through evidence the positive impact that integrated community care can have on tackling inequalities, improving care experiences and care outcomes 3. Illustrate how integrated care can and has been adopted in practice, and learn the lessons from these implementation experiences 4. Explore the essential design elements in how these new community-led approaches to care delivery operate and what this means for their ongoing organisation and management

5. When a common understanding of ICC is established, work with our delegations to adapt our learnings to our own contexts

2.2 Engaging people and communities as co-producers of health

Traditional curative and disease-based approaches to care are no longer effective and sustainable. Underserved and marginalised populations are being further excluded and isolated because of the socio-demographic trends of ageing, chronicity and lifestyle behaviours. A shift is needed towards a goal-oriented, person-driven care aiming at enhancing the quality of life of vulnerable individuals and improving population health amongst communities. Radical transformation is required to make better use of community assets and to break-down organisational, structural and cultural barriers that get in the way of effective collaborations. Improving access to community resources, information and social activities entails willingness from community stakeholders and policy-makers to enable real progress creating an environment for change.

Integrated Community Care (ICC) is an approach that seeks to improve quality of care and quality of life by engaging and empowering people as co-producers of health through mobilisation of community resources. ICC requires new cross-sectoral and interdisciplinary partnerships be formed between health and social care services, schools, volunteer organisations, local authorities and other resources found in communities and neighbourhoods. It also involves promoting and valuing the role of informal carers and families.

The evidence base for ICC is limited and we lack validated indicators for the evaluation of promising approaches. Yet, the summarised experience from small-scale projects from around the world demonstrate that the following approaches are related to successful implementation and outcomes of ICC:

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

2.3 Asset-based community development

At the heart of ICC is the assets-based approach to community development in the sense that people and communities come together to achieve positive change using their own knowledge, skills and lived experience. Asset Based Community Development (ABCD) is an innovative and sustainable strategy that recognises and build on the complexity of the human, social and physical capital that exists within local communities (1).

In every community, unrecognized resources remain in numerous domains: individuals, associations, institutions, physical space, exchanges, and culture. Keynote speaker Cormac Russell, (Managing Director of Nurture Development, Ireland) criticised the traditional way of approaching people in need for help: "*Take homeless people - why do we label people by what they don't have, a home? Every person has resources and we should start looking for them instead of their deficiencies".* Cormac Russell emphasized that ABCD is not about content perfection, rather it is about discovery and

connecting people at the micro-level to the macro-environment to support the community from within. This way, communities can drive the development process themselves by identifying and mobilising existing, but often unrecognised assets, and thereby respond to and create local economic growth.

A health asset is defined as “any factor or resource which enhances the ability of individuals, communities and populations to maintain and sustain health and well-being”. The following seven functions are suggested as essential for citizens to be able to collectively create greater community wellbeing (2):

1. Enabling health
2. Assuring security
3. Stewarding ecology
4. Shaping local economies
5. Contributing to local food production
6. Raising our children
7. Co-creating care

These assets can operate at the level of the individual, family or community as protective and promoting factors to buffer against life’s stresses”(3). In this approach, identified assets are matched with people or groups who have an interest or need in that asset. The key is to begin using and valuing the resources already existing in the community starting with what is right, not what is wrong.

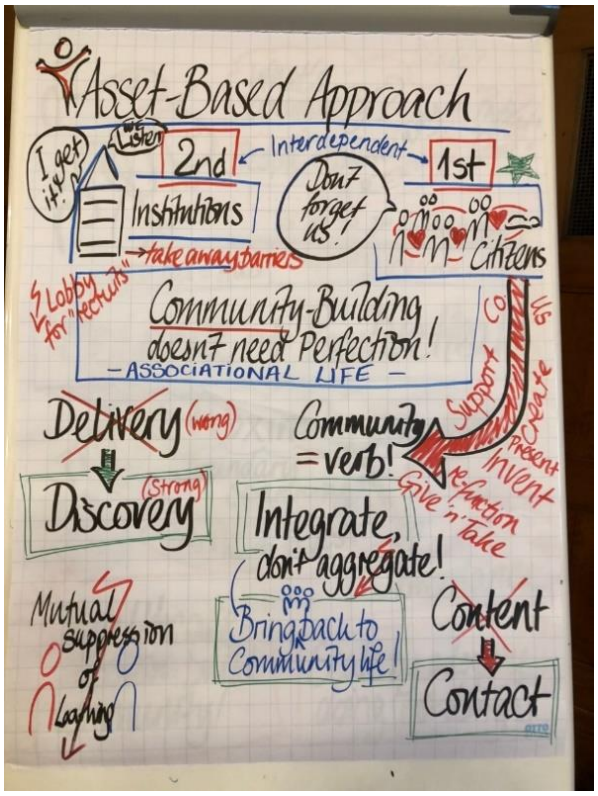

Figure 1. Visual drafted by the conference facilitator, Natasha Walker summarising the key note 'Putting community at the heart of integrated social care: an asset-based approach' by Cormac Russell

In his keynote speech *‘From medicine to positive health: how can community integrated care contribute?’* professor Jean Macq (UC Louvain, Belgium) raised awareness to ‘wicked’ problems, such

as poverty, that have exhausted the repertoire of the standard systemic policy approaches traditionally available to governments. Today, governments are increasingly looking for new options, and one approach receiving increasing attention is 'place-based' governance. Place-based solutions seeks to break down the 'wickedness' of broad and complex problems by dealing in detail with its different manifestations at the local level. There is an increasing demand for proximity providers contributing to the best balance between people life goals and enhancing social cohesion within communities.

Jean Macq referred to the 4P's medicine (Predictive, Preventive, Personalized and Participatory) as an approach that prioritises a technology-driven medicine, continuously adapting treatment to targets for individuals and he added that the mainstream driving force to establish healthcare priorities is not (only) to improve health, but it is much more about employment, security, professional turf conflicts and financial profit (4).

Professor Macq argued the need to move from an ego-system to an eco-system and referred to Scharmer and Kaufer's book *Leading from the emerging future*. What must end is the old civilisation and mindset of maximum "me" and maximum material consumption, to be conquered by a future where we tap into a deeper level of humanity of who we really are, and who we want to be as a society. It is a shift from an ego-system awareness that cares about the well-being of oneself, to an eco-system awareness that cares about the well-being of all, including oneself.

Figure 2. Visual drafted by the conference facilitator, Natasha Walker summarising the keynote 'From medicine to positive health: how can community integrated care contribute?' by Jean Macq

Key lessons learned from the two key note speeches
• Place based governance is different from a New Public Management approach in that local adaption happens through learning by doing - there is no one-size-fits-all solution. The learning process involves uncertainty and comprehensive system thinking. • Developing integrated community care is an adoptive process where existing boundaries are challenged and expanded, where patients become people, and where health is regarded a common good created in the community through connecting people and listen to their needs. As Cormac said: "*We don't have a health problem, we have a village problem*". • Clinical quality improvement and cost reduction is not only what matters; promoting equity in health and sharing community resources may give long term return by potentially decreasing cost of low-value or avoidable care mechanisms. • During the discussion following the key notes, a request for defining 'community' was raised. It was suggested that people must decide what community they belong to and we must accept that people can have different perceptions of what the word community means to them. • From the perspective of TransForm it is the ambition to come up with a general framework defining the key principles of integrated community care. The following principles are taken on board: ICC is relationship-based, place-based, citizen-led and moving from needs-based to asset-based approaches. It creates space for communities to articulate what they value, and health & care are co-produced within an interdisciplinary approach.

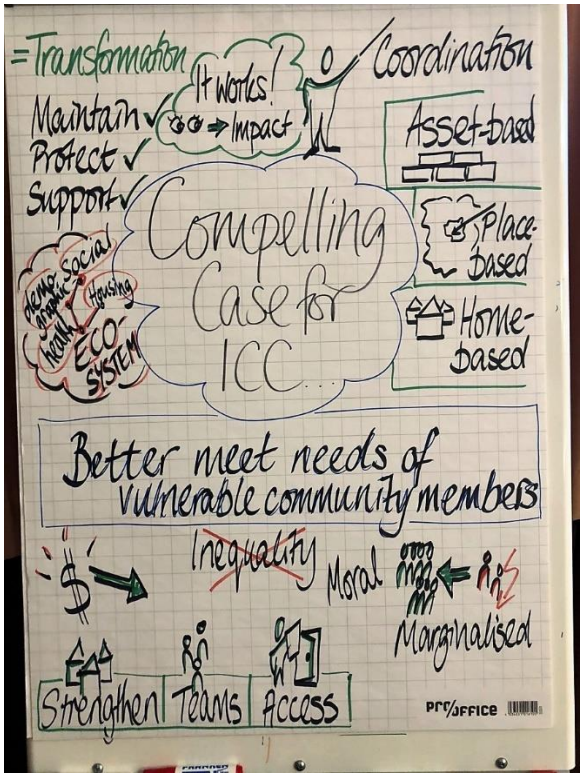

Figure 3. Visual drafted by the conference facilitator, Natasha Walker

3. Design and impact of ICC

This section of the programme aimed through two case study presentations to demonstrate different approaches taken to design and deliver ICC and the impact ICC could have.

3.1 Community Health Center Port Hohenstein (Reutlingen, DE)

Coordinator Barbara Steiner presented the case Gesundheitszentrum Hohenstein, a PORT (patient-oriented centres for primary and long-term care) concept to foster local adoption of the German guidelines for public health, launched in 2014. The PORT concept is funded by the Robert Bosch Foundation (please also see the summary from the cite visit to Health Centre PORT Büsum below).

Community Health Centre Hohenstein represents ICC as it engages a range of community stakeholders presenting local needs and possibilities. The local district of Reutlingen was presented as an example where the implementation of the public health guidelines was achieved by establishing a Working Group called "Healthy Community" which involved representatives from health insurance companies, medical associations, politicians, sports clubs, pension insurance, chamber of crafts, chamber of industry and commerce, educational establishments, support groups, district hospitals and the district office. The chairman of the committee is the district administrator.

A needs assessment was based on analysis of population data, current health infrastructure and supply of health-promoting offers and structures. Workshops were held with the citizens to gather ideas and visions, attracting and motivating citizens to be involved in the process and to coordinate regional supply planning. The vision is that health is a communal task generating economic growth.

The health centre has a multi-professional team composed of general practitioners, physiotherapists occupational therapists and medical consultants offering consulting services for professional and civic actors. A municipal health conference is arranged yearly, and the facilities are designed for people to meet, relax, and engage in physical activity and educational activities.

Their next steps will involve defining responsibility for development of infrastructure among private practices and the municipality and defining the professionals' roles and responsibilities. They are also working on defining how short- and long-term effects of their services can be measured.

3.2 Live well, feel better ("la Caixa" Foundation, ES)

The "la Caixa" Foundation programme was presented by Javier Yanguas, Scientific Director of the Ageing Programme in Spain. Yanguas explained that the project was motivated by several demographic changes: people live longer with multimorbidity and elderly are a heterogeneous group with different and changing expectations for life. The Live Well, Feel Well (LWFW) programme essentially empowers people to live the lives they want to live. It helps them find a sense of purpose and meaning to life. It is not just about doing activities, but rather about personal development rooted in: 1) enjoying the activities, 2) commitment to the activities and 3) a search for sense and meaning.

During 2016 and 2017, more than 30 000 elderlies participated in the *Live Well, Feel Well* (LWFW) programme and more than 2000 workshops were held throughout Spain. During weekly group sessions run by a specifically trained psychologist, participants' cognitive, emotional and social resources are explored and serve as the starting point for personal development and resilience. This approach involves challenging individual's comfort zones and taking risks to fight loneliness and interpersonal conflicts. In this model, vulnerability is regarded as a catalyst for change and as a means for decreasing loneliness, for example when participants are encouraged to reach out to family and close friends.

Even though LWFW works with older people, the programme does not apply geriatric theories or gerontology, but rather models of understanding the adult stage, such as self-determination theory, which serves as the project's theoretical framework. Self-determination theory recognise peoples' potential, self-sufficiency, emotional, social and cognitive status as resources for personal development. LWFW understands people want to be active participants in shaping their story, in their own personal development and in living a life coherent with their own values. LWFW helps to facilitate this by empowering people to commit to a search for a better life in terms of personal development.

Evaluation of the programme (quantitatively using online questionnaires and qualitatively through interviews and home visits) showed that after approximately one-year social and emotional loneliness scores had decreased in the intervention group, and wellness, self-efficacy, life-engagement and vital satisfaction improved. The LWFW program has shown capable of empowering elderly and increase their perception of living an active and meaningful life.

Key lessons learned from Health Center PORT Hohenstein and "la Caixa" Foundation
• Adopt to a continuous cycle of project assessment, assurance, evaluation and policy development and engage the participants in monitoring their progress. • Engage the citizens through workshops; ask for their ideas and let citizen's visions guide project development together with regional requirements. • Strive for interprofessional coordination although legal requirements, frameworks and financing are lacking. • A key challenge to western societies in assisting people to live valuable, meaningful lives is to combat social exclusion and unwanted solitude.

3.3 Experiences from local example projects of ICC

NetzWerk GesundAktiv

This project aims to support older people (70+) to live independently in their home for as long as possible through targeted counselling and support by a case worker in their homes. The network was motivated by a recognition that outreach services to patients in the community were not properly considered. Following this, a summer party was organised to connect older people and encouraging them to take part of the project together. Participants welcomed the initiative and requested more social activities. During the visit, the project team explained the design and development of their model, how patients are selected and included, the technological support and the evaluation model. A patient advisory council was established in October 2018 to have the patient and person voice better represented in the project.

Each participant undergoes an extensive preliminary geriatric assessment to target their needs, which is followed by an interdisciplinary case conference held with a primary care physician, geriatrician, sport scientist and social worker. Each participant is assigned a case manager for a period of minimum two years, and an electronic platform where they can send e-mails, make video calls and receive health information from their insurance provider is established.

Different health insurance funds are responsible for the continuous evaluation of participants' quality of life and the University in Bielefield for evaluating the project's cost-effectiveness. The project is funded by the German Innovation Fund of the Federal Joint Committee.

Key lessons learned NetzWerk GesundAktiv
• Concerns were raised by the project team on the process of selecting patients and the lack of family involvement. The latter aspect was partly explained by the fact that 90% of the participants were living alone or with their spouse and did not have family caregivers close by. • Their key learnings include having a strong team and project plan, a good involvement of relevant stakeholders and a common recognition that considerable efforts are needed to actively involve patients and the community.

Poliklinikk Veddel

Migrants comprise 71% of the population of the district of Veddel and a high percentage of the inhabitants does not have a health insurance. Chronic diseases are more prevalent compared to neighbouring districts and access to pharmacies, medical specialists, psychological counselling and general practitioners are limited. The policlinic consists of a general practice and a non-profit association financed by the statutory health insurance. A group of 10 volunteers run the clinic where students are involved in providing care and learning about migrant health the same time.

It took 8 years of theoretical work and conversations with different stakeholders before the policlinic could open. An open discussion café was arranged where citizens could voice their expectations and needs. At present, a multi-professional team provides free social and health counselling and psychological counselling in collaboration with universities, community organisations, NGOs and schools. The policlinic also provides home visits by nurses. The policlinic aspires to develop new approaches to tackle social determinants of health and in reducing inequalities through art and culture.

Key lessons learned Poliklinikk Veddel
• The clinic aims to map how people perceive their wellbeing within community, but the transient nature of the population renders an impact assessment difficult. • The project considers whether they should continue targeting only socioeconomically challenged people or whether it should be open for everyone. • The clinic is financially challenged, and new funding partners are needed.

CoResZon (Community Resilience Network)

Coreszon was founded in 2016 by University of Hamburg-Eppendorf and partnered with the Peter Möhrle Foundation, as well as several local and international refugee aid organisations. The goal of the initiative is to reduce mental health disparities among refugees through a resilience-focused approach. This approach is culture-specific and aims to lower participants' stress level by investing in self-help, relationships and offering a social supplement to the standard mental health service. Since April 2017 volunteers has provided personal assistance, counselling and training for refugees in Hamburg.

The team uses the Garden Method for Community Wellbeing, which implies improving participants' recovering skills from stress or post-traumatic stress disorder. They provide activities in German, English, Dari, Farsi and Arabic. The bottom-up experiences from the project are shared with stakeholders at community and agency levels.

Coreszon aims to lower the stress level of refugees by investing in relationships and offering social support, by increasing the ability to address self-care and making use of a first aid kit. There is a lot of

appreciation for their peer-to-peer work, but the conference participants pointed to a certain degree of ambiguity, embedded in the project. What is the final goal of moderating the impact of stress of refugees? Decrease the potential for violence or work on conflict resolution? Improve the quality of communication? At the end what's in it for the refugees themselves?

Overall Coreszon shows a high level of social entrepreneurship and is looking for a broader use of the Garden Method for Community Wellbeing in other settings. Mental health literacy is often lacking in the field of health promotion. An advisory council is now being recruited from relevant stakeholder groups to reflect on the possibilities for upscaling the Coreszon approach.

The Coreszon team are settled at the University Hospital. Although they tried to simulate how they connect with refugees and how they invest in building relationships, the hospital setting made it difficult to understand how the team actually work in refugee centres.

Key lessons learned CoResZon
• Sufficient time to build trusting relationships is important for project sustainability. • Resource allocations should be negotiated at agency level with stakeholder partners. • Make a point of partnering with people and organisations who can offer what you cannot and ensure that interests are transparent and negotiable. • Respond to and integrate participants input. Do not get over-attached to your plan at outset. Keep target outcomes in mind but be open for redefining these with your participants.

INVEST Billstedt/Horn

This project represents a "gesundheitskiosk" aiming to empower patients to take more responsibility for their health, decreasing the work load of general practitioners and increasing quality of care through connecting the medical and social sector. The gesundheitskiosk is a one-stop, walk-in clinic at street-level providing disease prevention and motivational counselling in eight of the most spoken languages in the neighbourhood of Billstedt/Horn. The initiative targets the whole population; from "parent-schools" in kindergartens to chronically ill elderly, as well as providing training of physicians, physician assistants and nurses.

In 2018 the kiosk has provided 921 first consultations, 700 follow-ups and 400 short consultations. Also, together with local health and social care providers the project has created a database covering activities and programmes which patients and other stakeholders can access. The planned evaluation of effectiveness and transferability will be led by the Hamburg Center for Health Economics. Outcome measures that will be provided are: population health, patient experience, health literacy, provider experience and per capita costs.

The project has invested heavily on developing cutting edge IT infrastructure where patients can share information with their healthcare providers and in developing an electronic medical record (EMR) that among others, facilitates collection of user data from fitness trackers and wearables. All providers and case managers connected through the network have access to the EMR, can share documents online or use telemedicine to communicate with each other and with patients.

The innovation Fund of the Federal Joint Committee has financially supported the project until the end of 2019, as well as numerous partners from the health, social, educational and municipal administration.

Key lessons learned INVEST Billstedt/Horn
• Inviting stakeholders to their facilities helped breaking the ice and build local physicians', social services' and clients' trust. Older physicians tend to be harder to bring on board and it is useful to reiterate the value and importance of the initiative. • Data privacy is challenging, and it may help to clarify what this means to people. It challenges the patients' trust because they must read and sign pages of privacy forms that took 1.5 years to develop together with lawyers (one for the insured and another for the uninsured). • The project team considered it difficult to measure savings attributed to the project, which is necessary in justification of future investments. The staff at the kiosk shared the following advice concerning this project's success: o Focus on regions with high needs and where the potential for cost reduction is high o Involve payers from the start and in everyday business o Involve local actors such as physicians and pharmacies early o Develop a multi-level change strategy and act on different arenas simultaneously o Continuously repeat why you are doing what you do

Wellengang Hamburg and AG Jump

Wellengang Hamburg is funded by donations and a local NGO (*ALADIN).* The project provides support and counselling for children living with parents with mental illness. Through collaboration with paediatricians, school, social services and psychiatrists, the project focuses on prevention, education and empowering families.

Children aged 8-17 years are taught how to handle their parents' burdens through an educational programme of 11 meetings. The children and their families, have played an active part in designing the curriculum, which involves building trusted relationships between the children and facilitators before moving on to strategies that empower and support the children. The structured set of sessions are developed in small groups to facilitate engagement. An "emergency plan" is worked out for particularly difficult family situations emphasizing that the child is not alone. Also, the programme focuses on teaching children self-worth and that they are not to blame for their parent's illness. The project facilitated the first parent-baby group for families with mental illness and their children under the age of 1 to support parent-baby communication in 2018.

Results from the evaluation (by The University Hospital Eppendorf) were not yet available at the time of the Hamburg conference. However, the project managers have experienced increasing publicity of challenges related to parents with mental illness and requests for experts' interviews and reports from media, all of which has helped raise awareness of the issues. Currently there is more demand for support than places available, and the project has met limitations in extending its reach due to the availability of trained staff and funding.

AG Jump (Junge Menschen mit Pflegeverantwortung)

The AG Jump is an initiative driven solely by volunteers to support young people up to 25 years of age who provide care for a parent, sibling, grandparent or other close relative with a physical, mental or cognitive health impairment. It is estimated that 1-2 students per class tend to be involved in supporting a family member with caregiving. Hence, AG Jump have initiated a pilot project that encourages cooperation between schools, health and social services to raise awareness of young carers and to develop and test various support tools to be used by professionals. AG Jump emerged

from an EU project called *Together for Young Adult Carers* and with latter support and recognition from Eurocarers. Narrative feedback suggests AG Jump is valued by the young carers that have participated.

The pilot has been difficult to implement as the staff at the local schools and in the municipalities do not recognise or lack knowledge about the needs of young carers. As a result, the project is vulnerable and the degree to which the services can be promoted across communities has been limited. AG Jump is fully reliant on volunteers and attempting to gain local grants and donations. They are currently developing educational material for the schools and have postponed the project to 2019 due to lack of funding.

Key lessons learned Wellengang Hamburg and AG Jump
• Links and coordination between formal mental health services and other support services are limited, partly because the role of children in supporting and coping within families with mental health issues is not formally recognised. • Word of mouth and raising awareness amongst communities through various channels (e.g. schools, media, leisure clubs etc) may reduce stigma and encourage young people to come aboard. • The environment through which to engage children must be handled with great sensitivity and security to ensure that details of individual cases are kept confidential within the cohorts of children that are supported. Relationships with families need to be carefully managed. • Engaging with young carers in communities requires the provision of support in a secure and empathetic environment, protecting individual's identity and the specific issues and circumstances they face. Still, it is possible to bring young carers together to form closer bonds, enabling peer-support.

Health Centre PORT Büsum (workshop at the conference venue)

Health Centre Port Büsum is part of the wider network of PORT registered centres (the Community Health Center Port Hohenstein is another example). It is owned by the municipality and provides multi-professional, continuous care to its community of app. 8000 inhabitants and app. 6000 tourists every year. Motivated by the shortage of primary care physicians, Port Büsum became the first community-owned practice in Germany. Büsum is a rural area where 60% of the population and neighbouring towns is 60 years or older.

The Robert Bosch Stiftung supports the maintenance and development of services of the centre to meet the primary and long-term care needs of the population. Today, more than 260 patients receive individualised geriatric care and about 7800 persons with chronic illness are treated at the centre each year. The staff, which includes a case manager, nurses, physiotherapists, osteopaths, medical assistants and physicians, provides telemedical supported home visits to patients with chronic heart disease, video consultations with specialists and professional training in different medical topics such as nutrition and relaxation methods. Nurses visit patients with chronic diseases at home and provide a medical assessment, in which data are sent to the general practitioner, to enable a faster diagnosis. Each patient is provided with a case coordinator, which secure the patient's rights through the special geriatric pathways. Patients at the centre receives information about relevant local self-help groups, social services, pharmacy services and community dietary counselling.

Key lessons learned Health Centre Port Büsum
• Changing professionals' culture towards a team-based approach has been a challenge and the future financial resources are not secured. Possible options for funding are the municipality or private insurance companies. • The centre has increased the attractiveness of the region for young doctors, and improved citizen engagement and social cohesion; however, evaluation of the health impact of the centre's services has not been performed.

3.4 Summary of experiences from the local projects

The site visits in Hamburg focused on innovative practices, in an early stage of development. Some of them are initiated by powerful key stakeholders and funded by the Innovation Fund (5), others are initiated by the community and being developed by passionate professionals and/or volunteers, looking for different funding sources. Being emergent cases, the focus was on the teething problems of setting up the project, bringing everyone together, creating a common understanding, getting started and gathering first learnings. In general, the projects could not demonstrate impact or outcomes yet. Some practices are looking for other impact frameworks, as the existing ones are not designed to capture the real impact on communities. Impact measuring of ICC requires other approaches and methodologies.

There was also a wide scope of what was understood as community and community involvement. Most sites are still dominated by health services and a clinical approach to service delivery, and most struggled with involving social, community or civil society services. The underlying challenges of the German system also became apparent, with a very pronounced fragmentation of the funding streams and provider organisations, a dominant role of physicians and consultants, as well as strong professional hierarchical structures.

Going forward, the TransForm project should look for local case sites that are more mature and able to demonstrate outcomes, as well as be more community-driven and better prepared for the exigencies of the conference participants.

The case sites presentations are available on www.transform-integratedcommunitycare.com

Figure 3. Presentation of the Millom example

4. Implementation of ICC

This section presented three case studies to demonstrate how ICC could be successfully implemented.

4.1 Presentation of successful cases of ICC: Jigsaw, Quartiers Solidaires and Millom

Jigsaw National Centre for Youth Mental Health

The charity-based Jigsaw National Centre for Youth Mental Health was presented by its director Joseph Duffy. Jigsaw promotes a prevention and early intervention approach to youth from 12 to 25 years experiencing mild to moderate mental difficulties in Ireland. Representing an example of ICC, the initiative is not institution-based but focuses on involving young people in decision making. For example, the organisation is closely guided by a nationwide network of 130+ volunteer Youth Advisors, aged between 16-25, who help guide the organisation's strategy, recruit people, inform research, ensure the organisation stays relevant to those it supports and are central to work in reducing the stigma that surrounds mental health.

Since 2008, 26 067 young people have been supported by more than 150 staff members. In 2017, 22 703 community representatives (i.e. service providers, volunteers, administrators, community members, etc.) took part in free of charge education and training workshops.

Jigsaw has proven sustainable thanks to rolling Governmental funding, the local involvement of managers, professionals, community leaders and the young people. The project has a platform for collecting user data (the Jigsaw Data System) used to demonstrate its impact towards policymakers.

An important factor in Jigsaw's successful implementation is the continuous support of managers in becoming agents of change and of professionals to change how they work in a new and transdisciplinary model.

Key lessons learned Jigsaw National Centre for Youth Mental Health
• When asking professionals and stakeholders to work in new ways, be prepared to fail, learn and try again. • Be transparent about the problem statement, your funding and plans for possible solutions. • Identify early adaptors and build relationships locally. Work with them and others will follow. However, do not stop at the local level, integrate the change at regional and national policy levels. • Seek to meet the policy makers and politicians – invite them to visit services and see first-hand the work being undertaken. Show them the solutions that you offer. • Define the roles of all partners. For example, empowering young people with a mental health issue may strengthen the attractiveness of your project/brand and secure its development according to their needs. • You will need evidence to convince policy makers and professionals.

Quartiers Solidaires by Pro Senectute Vaud

Pro Senectute Vaud is a public utility association from Switzerland in which purpose is to facilitate the integration of elderly people in their neighbourhood in order to improve their quality of life. The project "Neighbourhoods in Solidarity", presented by Marion Zwygart, has three main focuses: Ensuring that older adults can live with dignity by supporting them with necessary material aids equipment, encouraging physical activity in old age and offering social spaces for older people to meet to avoid isolation and loneliness.

Results from 2016 shows that Quartiers Solidaires had 82 permanent employees, 517 volunteers, 190 adapted housing apartments and arranged 6 975 sport and movement activities. The project has established several advisory groups consisting of stakeholders, inhabitants and local partners.

The one-year evaluation explored the reality of the elderly's' life and the work of healthcare professionals in the local communities through passive and active observation, interviews, forums and a diagnostic report. One of the outcomes was a diagnostic walk where the elderly, stakeholders and the project partners walked around in the neighbourhood together to observe the feasibility and accessibility for elderly to move about in the community. The project also convened an open forum where the public could attend to inform the project management and stakeholders about their needs which was later set into action, such as spaces to meet for coffee or a meal, playing board games, arrangements of common hikes, car sharing facilities, computer assistance and inter-generational activities. Currently, 7000 seniors from 19 municipalities are actively participating in Quartiers Solidaires. At the individual level, the project evaluation shows that Quartiers Solidaires has led to increased empowerment, welfare, happiness, quality of life and decrease in participants' perception of loneliness.

Reflections were shared among the delegates about the sustainability and transferability of the model. The Quartiers Solidaires is an example of a place-based intervention drawn upon local needs and resources.

Key lessons learned Quartiers Solidaires
At the community level, factors contributing to Quartiers Solidaires' success included: • taking collective decisions • respect for otherness and creating an arena for civil society to meet decision-makers from the public sector At the individual level, the project results include: • increased participation in community activities • improved physical and mental health, i.e. through improved social role and meaning, self-sufficiency, welfare, happiness and decreased loneliness

The Millom example

The project was presented by Professor John Howarth, System Clinical Leader in Millom, Cumbria and Deputy CEO NHS. The project was motivated by the one million miles of travels that were generated by the Millom population to have their healthcare needs covered and which consumed 59% of Millom's healthcare budget. In 2014, general practice had difficulties recruiting physicians and the community hospital was closed temporarily. More than 2000 people walked the streets in protest.

The Millom example consists of three main factors of success: Activated Individuals, carers and families; a community delivery team mobilised to take part of the leadership; and community impact on system leadership, architecture, culture, commissioning and provision.

Multiple social challenges such as adverse childhood experiences, disability, poor mental wellbeing, deprivation, isolation and substance misuse may hinder people to lead healthy lives. In Cumbria, a team of 19 Health and Wellbeing Coaches (HAWCs) have been trained in asset-based approaches to improve the lives of people experiencing complex challenges. The HAWCs initiative has shown to reduce anxiety, depression and smoking rates and increase income and social connection.

Howarth emphasised that all communities have health assets that can contribute to positive health and well-being. For example, through individuals' skills and knowledge, through friendships and good

neighbours, the public, private and volunteer associations and the physical, environmental and economic resources.

In two years, the project has achieved a 23.3% reduction in non-elective admissions and a 16.3% reduction in elective admissions.

Among other initiatives that has brought about Millom's success is the:

- New town newspaper "Around the Coombe", full of health promotion messages and distributed to 5500 households to generate local enthusiasm.
- Development of a new model of multi-disciplinary primary care having two NHS Foundation Trusts joining the practice as partners. A part of this model is generating salaried positions for GPs within an integrated care system.
- Cumbria Fire and Rescue Service who carries out 10,000 'Safe & Well' home visits every year to people aged over 65 in Cumbria and is now piloting the inclusion of an Atrial Fibrillation (AF) check as part of visits using a simple hand-held device, which will indicate whether someone requires further AF testing.

Key lessons learned The Millom example
• To combat the challenges in general practice, assuaging liabilities and financial worries is important. For example, by offering premises partly owned by the national health services and offer salaried GP positions within an integrated care system. Any surpluses of the primary care collaborative should be re-invested in the staff and in developing new roles. • Ensure that evaluation takes place alongside the initiative to inform the initiative's continuous improvement. • Never waste a crisis! When services are at risk, use this as a burning platform for change. • Social movements and asset-based approaches can solve seemingly intractable complex problems. A critical moment for the Millom example was inviting the protest group to join the leadership team, taking a lead on communications. • Health leaders led from the 'edge' of their organisations across boundaries and sharing success. The leaders were visible, displayed authenticity, an ability to move between strategic and tactical moves and built trust. This led to traditional power structures being dismantled.

5. Policy development

Over the course of TransForm's conference series, we seek to engage with policy-makers to understand what can be done to advocate for and support the development of integrated community care in practice. Sitting in small groups, five policy makers debated with conference delegates what strategies and tactics are necessary for developing an ICC friendly policy.

The five policy makers participating in the "Speakers' Corners" session were:

Anne Francoise Berthon, Mission Head, French Ministry of solidarities and health, ministerial delegation to innovation in health.

Caroline Verlinde, Deputy Director of Health at the Cabinet of the Flemish Minister for Welfare, Public Health and Family, Belgium.

Mattias Gruhl, Head of the Department of Health at the Hamburg Authority of Social Affairis, Family, Health and Consumer Protection, Germany.

Gisele Maillet, Government of New-Brunswick, Canada, Executive Director, Addiction and Mental Health Services Branch.

Augusto Ferrari, Member of the Piedmont Regional Government, as Commissioner for Social affairs and Housing.

5.1 Summary of Speakers' Corners session

The five policy-maker-led groups discussed six questions targeting policy development and implementation of ICC in different contexts. Following is a pointed summary of the five groups' discussions.

Q1. How do policy makers empower their communities?

- Early engagement – teaching children in schools
- Building community capacity by informing people and building network (universities, professionals, GPs etc.). People must support change. Many are satisfied with status quo. Citizens need to understand their role
- The right and guts to fail
- Combining regional programmes (framework) with grassroot initiatives

Q2. How are citizens involved as assets in policy making?

- NGO's part of the team
- New administrative units for public services
- Community advisory committees and connection to advocacy groups
- Policymakers can make new tools for governance processes
- Challenge the policy makers!
- By defining their needs for example through patient organisations or through practitioners

Q3. What are policy makers' visions for ICC?

- One common plan that is long-lasting, planned to go from project to reality
- Validation of the goals
- Strong relationships and strong leadership
- Extensive stakeholder consultation
- Let's go talk to the people
- Innovative and integrated service delivery, retrieving added value of combining silos
- Doing ICC without saying you're doing ICC
- Embedding ICC in the reorganisation of primary care

Q4. What slows policy towards ICC down?

- Working in silos and top-down approaches. Paradigm shift and cultural change is needed.
- Lacking a good common definition
- Our mandate is system focused
- Lack of people's trust and tools to get citizens involved beyond traditional actors
- Civil servants' stability vs political ambitions and possibilities
- Recruitment of patient organisations and the level of complexity to reach and involve the diversity of organisations
- Interference with local initiatives and the risk of frighten people as it is so difficult
- Changing legislation takes a very long time
- Difference between the corporate health system and the public system

• Balancing top-down approaches with people's freedom and alignment of micro and macro level
Q5. What do policy makers need from practitioners, researchers, municipalities and people to implement ICC? • Frontline workers that are well informed • Challenge from the people • Use the existing budget different – not introducing a new budget
Q6. How do policy makers use evidence? • Cost-effect analysis • Reduced waiting lists • Soft evaluation • Demonstration by KPIs • Mind that there is no perfect evidence for complex matters • Process quality versus outcomes

5.2 How can we take ICC forward?

This first TransForm conference sought to develop a common understanding of the meaning and logic of integrated community care, illustrate the potential for its positive impact, and examine how to successfully design and adopt innovative practices of ICC.

Lessons learned from the first conference show that progressing towards ICC requires complex system thinking where the dynamic inter-relationships and tensions between different actors are accounted for. 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 and nimble methods that incorporate how systems and individuals come together as a whole through exposure of multiple perspectives.

At the end of the conference, country specific discussions were held about how the delegates planned to transfer experiences from the first conference into future policy making and interventions.

Recapping all the conference activities, the following emerging themes and key principles reflected delegates' common understanding of ICC:

- Implementing ICC requires a paradigm shift and a new narrative.
- The line between citizens and patients becomes blurred.
- ICC development must build upon local needs and resources and involves an ongoing process of planning, learning and evaluating together with the people. New, bottom-up methodologies are necessary to engage citizens in the processes and in the discovery of community perspectives and assets.
- Recognize and value the essential role of people and community engagement.
- Targeting social determinants of health is not enough; community resilience is created by establishing new community networks.
- ICC calls for the implementation of place-based governance: local horizontal governance structure for comprehensive solutions.
- Mixed financial mechanisms are required to sustain and roll-out innovations in integrated community care.

- Be aware of the potential misuse of ICC to transfer the burden to the informal sector, without means. Value the essential role of policy and policy-makers in providing an enabling platform to support the adoption of integrated community care in practice.
- The ICC approach requires patience and trust. It may take time to realize returns and benefits.

5.3 From communities to families and individuals

The second TransForm conference is set out to explore how people can be empowered to express their diversity of perspectives, needs and resources. Supporting the voices of micro level actors in the communities is a way to connect policy and practice and demonstrate how a different role of individuals, carers and families can improve quality of life, care experiences and outcomes. This will be achieved by taking both a needs-based and an asset-based approach.

Important questions that still need to be solved and that will be addressed in the second TransForm conference are:

- What do individuals, carers and families value in supporting their health and wellbeing?
- What are the key tools and approaches to empowering and engaging individuals, carers and families to meet the objectives of integrated community care?
- What impact does micro level engagement have on quality of life, care experiences and care outcomes?
- What competencies are necessary for professionals and decision-makers to be able to work in this new environment?
- What are the key issues and challenges that will be faced by different stakeholders (e.g. policy-makers; managers, professionals, community leaders, individuals and families) in the implementation of people-driven care and the potential approaches and solutions that may be adopted to support transformational change?

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Figure 4. TransForm conference participants

Appendix I – List of participants

	Name	Organisation	Country
1	Patricia Adriaens	Fibrona, Gi(d)ts, Fund Dr. Daniel De Coninck	Belgium
2	Sibyl Anthierens	University of Antwerp – Research in Primary Care	Belgium
3	Paulina Ballbè	Universitat Pompeu Fabra	Spain
4	Corinne Bebin	City of Versailles	France
5	Anne-Françoise Berthon	French ministry of Health	France
6	Loïc Biot	Ville de Grenoble - Direction santé publique et environnementale	France
7	Monica Blotevogel	University Medical Center Hamburg-Eppendorf/Community Resilience Network (CORESZON)	Germany
8	Thomas Boeckx	Flemish Agency for Care and Health – Primary Care Team	Belgium
9	Tom Braes	Zorgnet-Icuro, Flemish Network of Health Care Facilities	Belgium
10	Sigrid Brisack	Aidants Proches - Informal Carers Association	Belgium
11	Peter Burggraeve	VIVES, Health Care Research & Development	Belgium
12	Valeria Cappellato	Compagnia di San Paolo	Italy
13	Alice Casagrande	Fédération des Etablissements Hospitaliers & d'Aide à la Personne Privés Non Lucratifs (FEHAP)	France
14	Luana Ceccarini	Associazione “La bottega del Possibile”	Italy
15	Victoria Conconi	Robert L. Conconi Foundation	Canada
16	Giuseppe Costa	ASLTO3 – SC a DU Servizio Sovrazonale di Epidemiologia	Italy
17	Koen De Maeseneir	Flemish association of Community Health Centres VWGC	Belgium
18	Paul De Munck	Groupement Belge des Omnipraticiens	Belgium
19	Martine Delfosse	Wit-Gele Kruis West-Vlaanderen (Home nursing)	Belgium
20	Anneke Denecker	King Baudouin Foundation	Belgium
21	Valentina Di Pietro	ActionAid International Italia Onlus	Italy
22	Hanneli Doehner	Wir pflegen – Interessenvertretung begleitender Angehöriger und Freunde in Deutschland e.V.	Germany
23	Joseph Duffy	Jigsaw- National Centre for Youth Mental Health	Ireland
24	Laurent El Ghozi	Elus, Santé publique et Territoires	France
25	Karine Fauria	BarcelonaBeta Brain Research Center, Fundació Pasqual Maragall	Spain
26	Elena Fernández Gamarra	Independent Consultant	Spain
27	Mar Ferrador	“la Caixa” Foundation	Spain

28	Augusto Ferrari	Piedmont Regional Government	Italy
29	Bernhard Gibis	Kassenärztliche Bundesvereinigung (KBV)	Germany
30	Luc Ginot	Agence régionale de santé (ARS) Ile-de-France	France
31	Federica Giuliani	Municipality of Turin, Social Services Division	Italy
32	Pasquale Giuliano	Local Health Authority Asl TO 3	Italy
33	Jodeme Goldhar	The Change Foundation	Canada
34	Bénédicte Gombault	King Baudouin Foundation	Belgium
35	Nick Goodwin	International Foundation for Integrated Care (IFIC)	United Kingdom
36	Nina Gramunt	BarcelonaBeta Brain Research Center, Fundació Pasqual Maragall	Spain
37	Antoine Groulx	Ministère de la Santé et des Services sociaux du Québec	Canada
38	Matthias Gruhl	Hamburg Authority of Social Affairs, Family, Health and Consumer Protection	Germany
39	Stephanie Häfele	Robert Bosch Stiftung	Germany
40	John Howarth	University of Central Lancashire	United Kingdom
41	Mélanie Hubault	Fondation de France	France
42	Marco Kellerhof	Hamburg Authority of Social Affairs, Family, Health and Consumer Protection	Germany
43	Danielle Kemmer	Graham Boeckh Foundation	Canada
44	Bernadette Klapper	Robert Bosch Stiftung	Germany
45	Alfonso Lara Montero	European Social Network	Belgium
46	Sophie Lasserre	Fondation de France	France
47	Christoph Luckmann	Gesundheit für Billstedt/Horn (UG)	Germany
48	Lüdtke Thies-Benedict	Die Schwenninger Krankenkasse	Germany
49	Jean Macq	Université Catholique de Louvain, Institute of Health and Society	Belgium
50	Gisèle Maillet	Government of New-Brunswick	Canada
51	Ruth Mengel	Ärztezentrum Büsum	Germany
52	Benoit Mores	Cabinet of the Minister of Social Affairs and Public Health	Belgium
53	Thomas Nebling	Techniker Krankenkasse	Germany
54	Patrick Orth	Aids Hilfe Hamburg	Germany
55	Idrissa Omer Ouedraogo	Aids Hilfe Hamburg	Germany
56	Caroline Piguet	Pro Senectute Vaud	Switzerland
57	Karine Pouchain-Grepinet	Fondation de France	France

58	Marion Quach-Hong	Fédération des acteurs de la solidarité	France
59	Gerrit Rauws	King Baudouin Foundation	Belgium
60	Anita Reboldi	Compagnia di San Paolo	Italy
61	Cormac Russell	Nurture Development	Ireland
62	Peggy Saïller	Network of European Foundations (NEF)	Belgium
63	Antoni Salvà	Fundació Salut I Envelliment UAB	Spain
64	Thomas Sannié	Association française des hémophiles	France
65	Stefan Schäfers	King Baudouin Foundation	Belgium
66	Nathalie Senecal	Fondation de France	France
67	Sanja Simic	Robert L. Conconi Foundation	Canada
68	Monica Sorensen	International Foundation for Integrated Care (IFIC)	United Kingdom
69	Viktoria Stein	International Foundation for Integrated Care (IFIC)	United Kingdom
70	Barbara Steiner	Health Care Centre Hohenstein	Germany
71	Jost Steinhäuser	University of Lübeck	Germany
72	Julika Stich	Young Helping Hands	Germany
73	Livio Tesio	Regione Piemonte	Italy
74	Yvan Tourjansky	Union Régionale des Professionnels de Santé Masseurs-Kinésithérapeutes d'Île-de-France (URPS KINE IDF)	France
75	Hendrik van den Bussche	University Medical Center Hamburg-Eppendorf, Institute and Policlinic of Primary Medical Care	Germany
76	Thérèse Van Durme	Université catholique de Louvain, Institute of Health and Society	Belgium
77	Hendrik Van Gansbeke	Wit-Gele Kruis van Vlaanderen (Home nursing)	Belgium
78	Tinne Vandensande	King Baudouin Foundation	Belgium
79	Tom Verhaeghe	Federal Ministry of Public Health	Belgium
80	Caroline Verlinde	Cabinet of the Flemish Minister of Health, Welfare and Family	Belgium
81	Natasha Walker	International Facilitation and Communication	Germany
82	Javier Yanguas	"la Caixa" Foundation	Spain
83	Marion Zwygart	Pro Senectute Vaud	Switzerland