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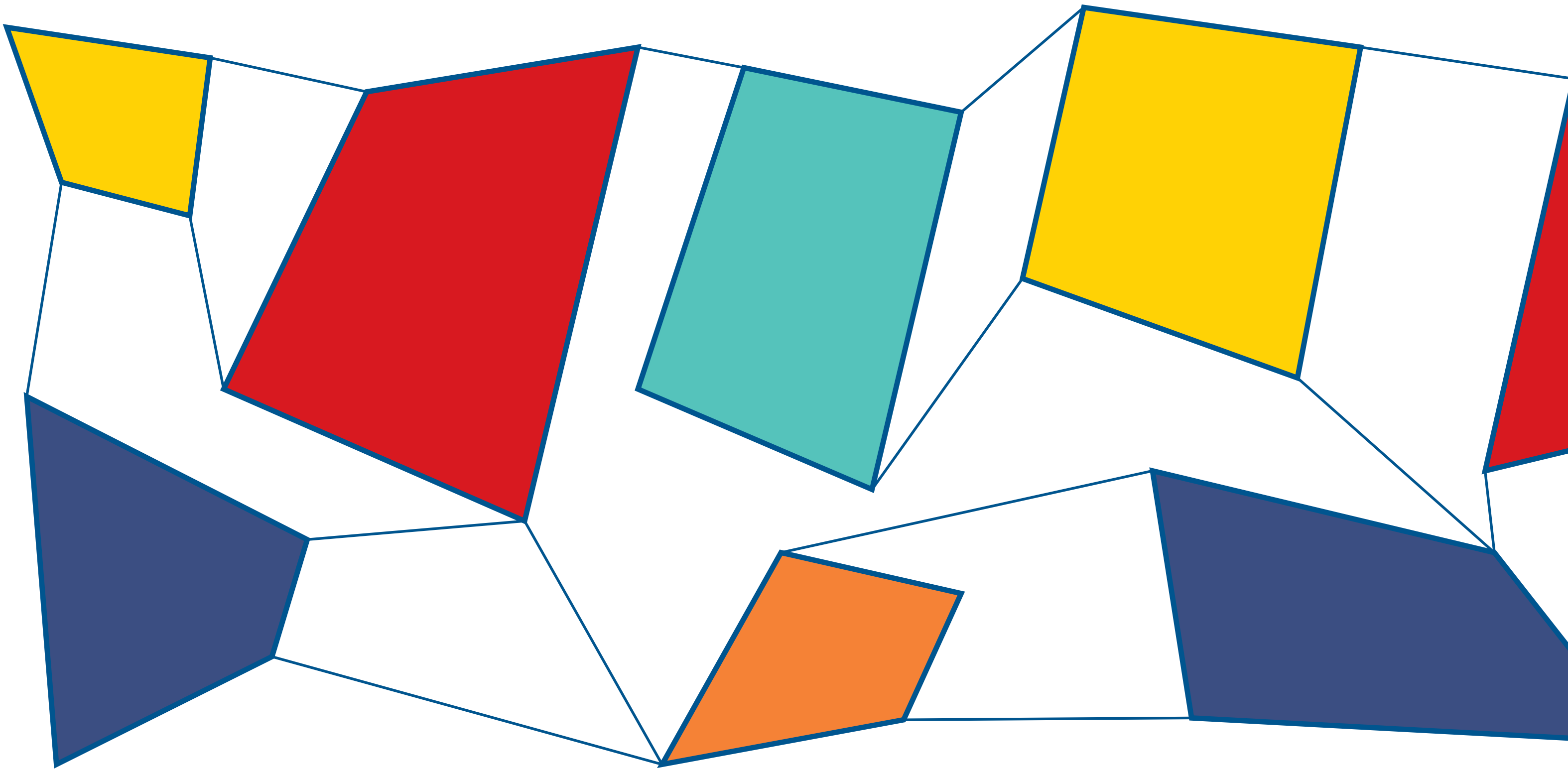
Health 2020 priority area four: creating supportive environments and resilient communities

A compendium of inspirational examples



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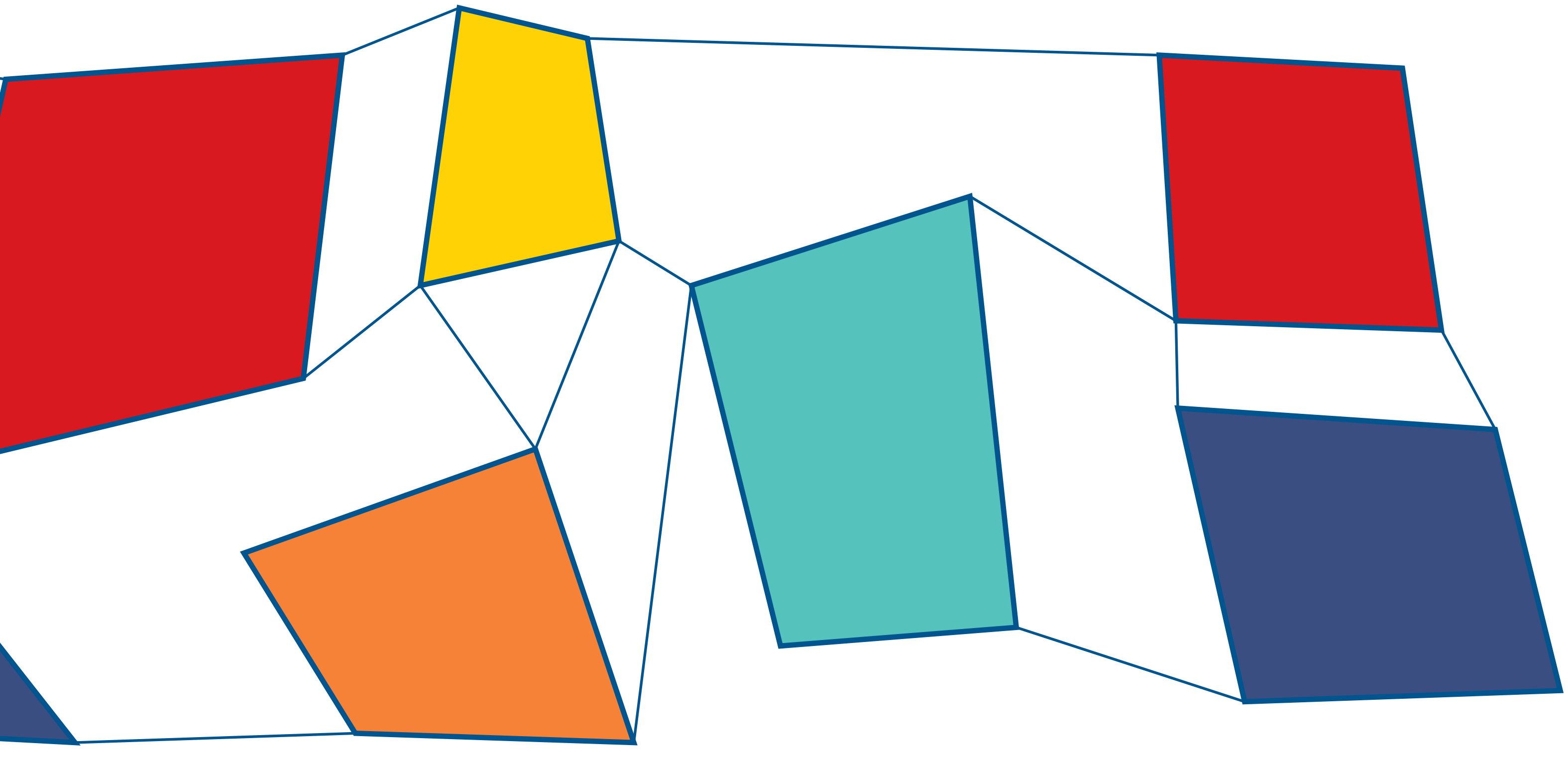
Editor: Erio Ziglio



Abstract

This Compendium provides inspirational examples of building resilience at individual, community and system levels. It describes the innovative, on-the-ground actions taken by 13 countries to create supportive environments for strengthening resilience and its link to health and well-being outcomes. The examples, primarily gathered from community initiatives, are linked to the four types of resilience capacities: adaptive, absorptive, anticipatory and transformative. The Compendium covers a wide range of topics such as the role of resilience building in addressing human rights, health inequities, and environmental hazards and threats; and health-related topics such as communicable and noncommunicable diseases.

Creating resilient communities and supportive environments for population health and well-being is one of the priority areas of Health 2020. Resilience is also a key element in achieving the Sustainable Development Goals. The Compendium follows and expands on two WHO publications released in 2017: Building resilience: a key pillar of Health 2020 and the Sustainable Development Goals and Strengthening resilience: a priority shared by Health 2020 and the Sustainable Development Goals.

Keywords:

COMMUNITY PARTICIPATION

RESILIENCE, PSYCHOLOGICAL

SOCIAL SUPPORT

EUROPE

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ISBN 978 92 890 5323 5

Text editing by Nancy Gravesen
Book design by Marta Pasqualato
Printed in Italy by AREAGRAPHICA SNC DI TREVISAN GIANCARLO & FIGLI

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Foreword

Since the endorsement of Health 2020: the European policy framework for health and well-being in 2012, I have noticed an increasing appreciation of both its rationale and content by policy-makers, health system and public health experts, civil society and the research community. The strategic objectives that characterize Health 2020 and its four cross-cutting priorities provide a sound and inspirational guide for improving health policy and achieving better health and equity outcomes in the 53 Member States of the WHO European Region. Health 2020's priority area four – creating supportive environments and resilient communities – is key to our efforts to modernize public health systems and increase the effectiveness of our actions to promote population health and avoid unacceptable health inequities.

Today, with the political adoption by the United Nations General Assembly of the Sustainable Development Goals (SDGs), everyone realizes how right and forward thinking we were to have included in Health 2020 the need to strengthen community and system resilience. Strengthening resilience is central to all 17 SDGs.

This Compendium of inspirational examples of action that strengthen resilience follows two WHO reports published in 2017. The first, Building resilience: a key pillar of Health 2020 and the Sustainable Development Goals – Examples from the WHO Small Countries Initiative, *explained the concept of resilience and its implications for health at three levels: individual, community and system. The second,* Strengthening resilience: a priority shared by Health 2020 and the Sustainable Development Goals, *analyses the synergies between Health 2020 and the SDGs. This report gives evidence that achieving the SDGs requires the search for structural processes and scientifically robust solutions to address the vulnerabilities of this world. This implies resilience-building processes at all levels. It requires resilient citizens, communities and societies. It also requires resilient systems to handle existing or potential vulnerabilities, shocks and disturbances. Thus, the report describes four types of resilience capacities: adaptive, absorptive, anticipatory and transformative. With these three publications, I wanted to make it easier for countries and their policy-makers to appreciate what resilience is about and its applicability to improve the effectiveness of health action.*

I am happy that the examples contained in this Compendium come from different contexts covering experiences in northern, southern, western and eastern Europe. Many valuable lessons and strategies can be distilled from the inspirational examples of action outlined in the Compendium. Among these, I would like to draw attention to the need to use a so-called resilience lens when designing, implementing, monitoring and evaluating health action within health care practices and public health interventions. The examples also help us to recognize the urgent need to review current practices and develop appropriate skills and know-how to promote health and reduce health inequities. Strengthening resilience requires a health workforce that is skilful in developing the types of resilience capacities and processes described both in this Compendium and in the other two publications mentioned above.

It is my hope that the collection and analysis of practical actions to strengthen individual, community and system-level resilience will continue both in WHO and in countries. This will allow the literature and strategies on strengthening resilience to grow. It will be instrumental in providing individuals, communities and systems more control of their lives and organizational circumstances, and better preparing them to confront unexpected adversity and risk. The implementation of Health 2020 and the achievement of the SDGs are critical to these endeavours.

Dr Zsuzsanna Jakab
WHO Regional Director for Europe

Acknowledgements

This Compendium was put together by Dr Erio Ziglio, Honorary Professor at the Health University of Applied Sciences Tyrol, Austria, and Visiting Professor at the Glasgow Caledonian University in London, United Kingdom. Special thanks go to all who contributed to the various inspirational examples contained in the Compendium. Many thanks also to those who allowed WHO to utilize the photographs and other materials published in this report. A special word of thanks goes to Ms Emily Hughes Ziglio and Professor Flavio Lirussi, former Senior Adviser, WHO, and Member of the Scientific Committee of the Italian Society for Health Promotion, for their excellent work in searching and analysing several aspects of the scientific literature on resilience and its impact on health and well-being.

WHO staff members provided suggestions for the final format of the Compendium and were involved in the writing of some inspirational examples. Among them, the coordination provided by Dr Francesco Zambon was key throughout the various stages of work resulting in this publication.

Background

This Compendium follows two WHO publications on resilience released in 2017. One focused on small population countries and outlined the rationale for the inclusion of resilience strengthening as one of the key priorities recommended in Health 2020 (1). It provided a historical review of the development of resilience research and its links with health and well-being. It identified three levels of action for strengthening resilience: individual, community and system. Three examples of action from small population countries were an important feature of that publication.

The second publication focused on the rationale of prioritizing resilience in both Health 2020 and the Sustainable Development Goals (SDGs). It was launched at a special side event of the 2017 WHO Regional Committee for Europe in Budapest, Hungary (2). Among other issues explored, this publication showed the relevance of resilience – mainly system-level resilience – in all 17 SDGs (3). The publication presented four types of resilience capacities. Such capacities are described in the literature as *adaptive*, *absorptive*, *anticipatory* and *transformative*. In line with Health 2020, the publication maintained that the three levels of resilience (individual, community and system) and these four capacities are key for effective public health policies and programmes.

By reviewing the scientific literature in the field of resilience, these two 2017 WHO publications point out that *adaptive* capacity refers to the ability of individuals, communities and systems to adjust to adversity, disturbances and shocks. *Absorptive* capacity is the ability to absorb and effectively cope with such disturbances and adversities. It is the capacity of individuals, communities and systems to manage and recover from adverse conditions. This is done by drawing on available skills, assets and resources. *Anticipatory* capacity is the ability to predict and reduce disturbances and risks by means of proactive action to minimize vulnerability. Finally, both publications indicate that the transformative capacity applies mainly to systems, as in the 2030 Agenda for Sustainable Development. *Transformative* capacity is the ability of systems to transform their structures and means of operating to better address change and uncertainty. It is the ability to develop (new) processes and practices that are better suited to new conditions.

Until very recently, most of the resilience research literature has focused on adaptive and absorptive capacity. However, in public health, anticipatory and transformative capacities are critical for effective interventions impacting on health and well-being outcomes. For example, the speed of technological and medical breakthroughs or cultural and demographic changes can render existing policies and practices rapidly obsolete or untenable, hence the relevance of such capacities (4). Research shows that effective public health interventions and health system developments require a policy environment that overcomes sectoral boundaries and enables integrated programmes (5,6). This is closely linked to resilience as a transformative capacity.

The relevance of resilience for advancing practice in public health

Health 2020 states that building resilience is a key factor in protecting and promoting health and well-being at both the individual and community levels. It argues that health outcomes are closely linked to the conditions in which individuals are born, grow, work and age (7). These conditions also influence resilience building. Strengthening resilience is a process that should accompany individuals and communities throughout the life-course. They need to be effectively supported to develop capacities to adapt, absorb, anticipate and manage their life circumstances in the context of change, uncertainty, adversity or in the face of new life opportunities. Health 2020 maintains that resilient communities respond proactively to new or adverse situations; prepare for economic, social and environmental change; and deal better with crisis and hardship.

What factors facilitate the development of resilient communities? What exactly is meant by resilience? Various health-related definitions of resilience can be found in the scientific literature, and they have been reviewed in the two WHO 2017 publications mentioned above (1,2). Notwithstanding their differences, they all point to the fact that resilience is connected to processes and skills that result in good individual and community health outcomes in spite of negative events, serious threats and hazards (1,2).

More recently, this definition has been broadened to include the resilience of social systems, including the health system and public health. Resilience is thus associated with the capacity of systems to absorb, adapt, anticipate and transform their practices when exposed to external or internal threats and vulnerabilities. Such capacity applies also to the ability of systems to forecast shocks that may bring about new challenges and opportunities (8). System resilience is therefore the capacity to transform practices and methods of operation and still retain control over the system's remit and the pursuit of its primary objectives and functions (9). A number of studies both in Europe and globally have looked into how to make health systems, including public health, more resilient (5,6).

In order to achieve the protective and promoting health objectives of public health, system resilience ought also to be a pro-active capacity that incorporates both anticipatory and transformative elements. Public health is now confronted with challenges that often transcend traditional practices and approaches. In order to promote health and create conditions of equity, radical change is often needed and called for. To achieve this, anticipatory and transformative resilience capacities have to become fundamental characteristics of public health policy-making (4).

Public health has a central role in advocating and pursuing action to strengthen resilience at individual, community and system levels. When using the term "resilience" in the health field, two factors need to be specified. The first is the level or context in which the term is used, i.e. whether it refers to the individual, community or system level of resilience. The second is the processes involved in strengthening resilience. The latter needs to be backed up by sound evidence that the proposed processes affect resilience and at what level. Any unwanted side-effects that may arise as a result of measures taken should also be highlighted. Needless to say, processes and measures will vary according to the level of resilience to be strengthened.

Finally, as pointed out in previous WHO publications, resilience is not a special asset with which someone is born; other external factors are critical (2). Resilience capacities can be developed over the life-course (1). A briefing paper on the relevance of resilience for public health summarizes this in a very effective way. It states that resilience is a process that involves individuals and communities supported by a wide range of resources to adapt, absorb, anticipate and transform challenges they face (10). Governance for health and well-being is also critical (11).

Understanding the processes that strengthen resilience is key to public health. Consequently, policy-makers with a role in public health should not only concentrate on emergency response to help communities "get back on their feet". Most importantly, they must activate processes for strengthening resilience so that communities can anticipate and actively find solutions to problems and challenges (10). Resilience can therefore be seen as both a process and an outcome. The latter is about the result of a process that helps individuals and communities become forward thinking and able to see the world and circumstances in which they face problems and discontinuity as understandable, and their action as manageable and meaningful. As such, the concept of resilience is much related to Aaron Antonovsky's concept of "sense of coherence" (12). The notion of "being in control" despite changed circumstances is also key in order to identify and strengthen processes that promote resilience (13).

It is hoped that the inspirational examples highlighted in the Compendium will provide insights into these resilience-related processes and outcomes.

Focus of the Compendium

The Compendium provides the reader with practical examples of actions that strengthen resilience and build supportive environments for population health and well-being. The information is primarily gathered from community initiatives and described in a narrative format. The term "inspirational example" is used to indicate action that is innovative and could be of interest for stimulating similar initiatives in other European settings.

The selected inspirational examples cover a wide range of actions that produce community- and system-level resilience. Each example highlights the supportive role and innovative practices performed by communities – often actively supported by public health institutions – that aim to strengthen resilience. In several examples, the action was generated entirely from bottom-up community efforts, with only minor or no direct support from health institutions. In some cases, action was initiated from within the health sector. In others, it was the result of cooperation, coordination and integration of efforts with other sectors. The selected examples add to the three country examples analysed in the 2017 WHO publication on resilience and small population countries (1).

In the majority of these examples, actions were the result of spontaneous, bottom-up community initiatives. As such, they were not implemented as part of a research project following rigid scientific protocols. Only a few examples include a monitoring system that measures the impact built into the activities. Nevertheless, it is hoped that the innovative and inspirational content of these initiatives is clearly highlighted by the narrative inquiry style adopted in the Compendium (14). Narrative inquiry is a research approach that is well-known in social research and is increasingly used in policy and programme analyses and case studies (15). Each example attempts to describe: the action undertaken; the resilience-related issue that the action aimed to address; and the impact and lessons learnt in the process of strengthening resilience.

Format of the narratives

Given the diversity of the stories selected, it was impossible – if not counter-productive – to utilize a rigid template to describe the inspirational examples. Nevertheless, efforts have been made to present the inspirational examples in a way that helps readers to understand:

- the issue the action highlights;
- how the issue was perceived and framed;
- the relevance of the issue to individual and population health;
- the types of action undertaken;

- the supportive role, if any, performed by public health and health systems;
- the impact achieved;
- the challenges faced and the enabling factors that came into play in order to innovate practice for resilience strengthening; and
- the main lessons that can be distilled from the narrative that could be of interest to a wider European and international audience.

Thus, the general structure of the narrative used to describe the inspirational examples is based on four sections: the issue, the action, the impact and lessons learnt.

Classifying and presenting the examples in the Compendium

This Compendium collects examples of action undertaken in WHO Member States that aim to strengthen resilience. Such examples are described to illustrate some current efforts in strengthening the three levels of resilience and the four types of resilience capacities.

The Compendium describes examples of strengthening resilience collected in the following European countries: Austria, Bulgaria, Denmark, Finland, Italy, Kyrgyzstan, the Republic of Moldova, the Russian Federation, Spain, the former Yugoslav Republic of Macedonia and the United Kingdom (England, Scotland and Wales). Thus, it covers experiences from different parts of Europe.

The Compendium covers a wide range of topics such as the role of resilience building in addressing human rights (e.g. people with disability), health inequities, environmental hazards and threats; and health-related topics such as communicable and noncommunicable diseases. Most importantly, the Compendium has examples that bridge health and development issues. The latter are crucial for both Health 2020 and the SDGs.

In addition to European experiences, the Compendium includes two testimonies from outside Europe. Australia and Canada were selected as they provide interesting insights and learning for the European audience.

The Compendium leads with the testimony of a well-known international expert with extensive clinical, public health and policy-making experience. Professor Sir Harry Burns, former Chief Medical Officer for Scotland, offers a passionate testimony that shows the relevance of strengthening resilience and the role of health professionals as partners with communities in the co-production of health and in the reduction of health inequities (Part 1). Part 2 has six examples that show how building resilience can be achieved by developing and sustaining partnerships between institutions and communities. The narratives in Part 3 describe building resilience by community action and bottom-up efforts. Part 4 shows how to strengthen resilience at system level, both nationally and locally. Part 5 illustrates experiences from two countries outside Europe and Part 6 offers conclusions and the way forward.

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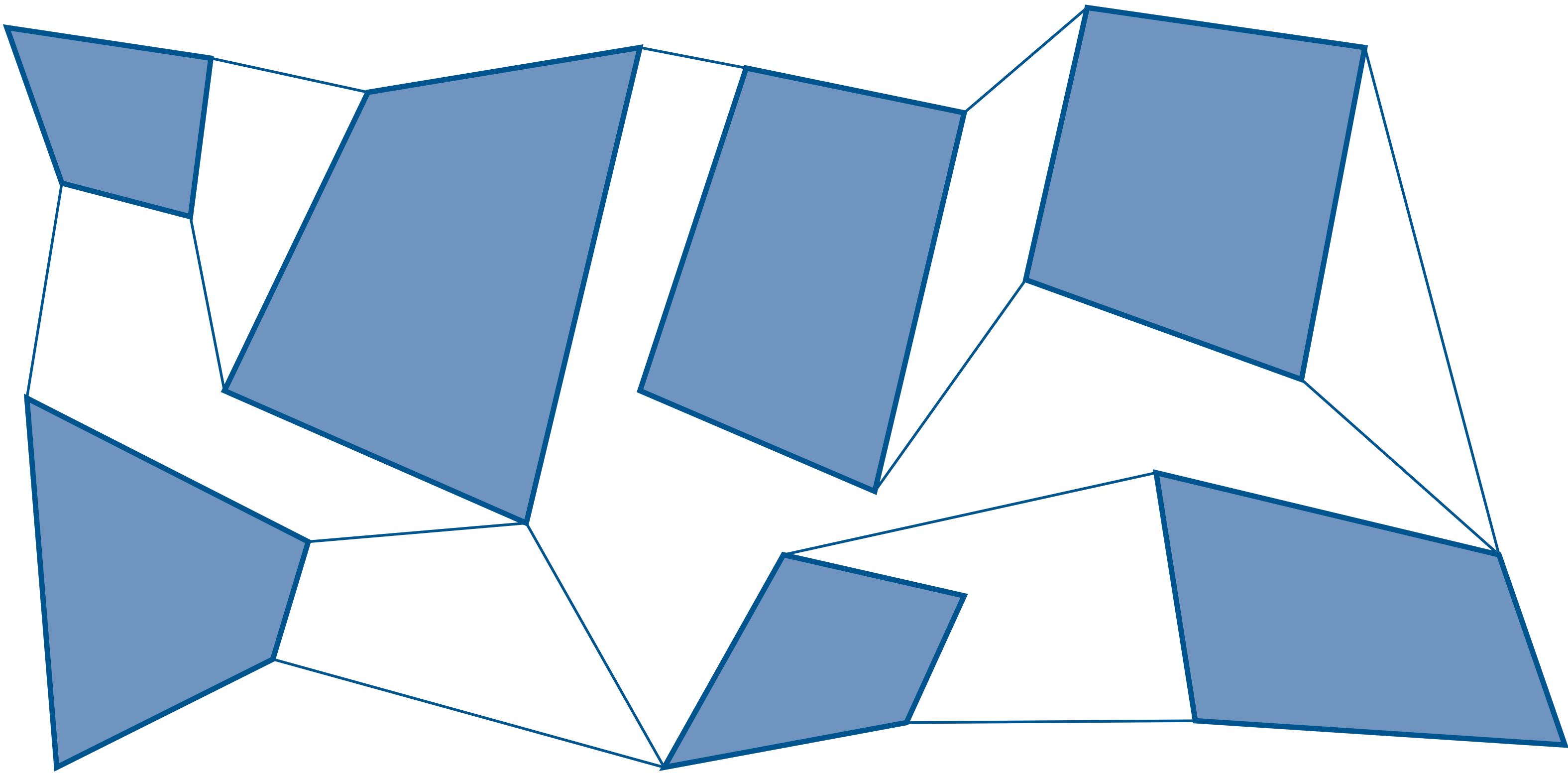
Part 1. A testimony from a public health professional

This Compendium starts with a testimony from Professor Sir Harry Burns, former Chief Medical Officer for Scotland. The testimony provides evidence as to why institutions and those involved in public health and policy-making should be better equipped to strengthen resilience and ensure people gain more control over their lives.



United Kingdom (Scotland). The journey to a healthy and resilient population

Author: Professor Sir Harry Burns

University of Strathclyde, Former Chief Medical Officer for Scotland

Abstract

This section outlines the thinking that is developing in Scotland as it attempts to transform the lives of people who are struggling with adversity. Many studies of the determinants of health and well-being in the deprived communities of Glasgow – Scotland's largest city – have been undertaken. Several studies have also been undertaken over the last few decades to try to understand how best to create well-being and resilience across the whole population. Most of this work has been carried out in the communities of Glasgow, but their conclusions are generalizable to the whole population of Scotland. It can be argued that such conclusions are relevant to other European populations which have experienced high levels of social and economic adversities, economic austerity and hardship.

This testimony by Professor Sir Harry Burns describes the social and political drivers of inequality in Scotland. Professor Burns also outlines the approach that should be used by communities to reverse the impact of policies which reduce the capacity of people at the lower end of the social scale to take control of their lives. Creating supportive environments for resilience building that supports people to feel more in control of their lives is key to making change happen. Being part of this journey has been an extremely enriching experience for Professor Burns throughout his professional life and during his time as Chief Medical Officer for Scotland.

The issue: Glasgow's decline in wealth and well-being

For the first 15 years of my medical career, I was a surgeon working in Glasgow, Scotland. As a surgeon, my perspective on improving health was very much focused on detecting and treating illness. There was plenty of illness to work on. The poorer communities in the city had remarkably high levels of ill-health which brought them to the attention of my hospital. It was impossible to ignore the disparity in disease between the affluent and deprived areas. Conventional medical thinking suggested that poor people chose the type of lifestyles that caused their ill-health. The history of health in Glasgow is full of descriptions of ill-health associated with social circumstances, and it was clear that further study of the link between deprivation and the serious health problems of the city was necessary.

In the first half of the 20th century, Glasgow was a thriving industrial city with high levels of male employment in shipbuilding, steel making and other heavy engineering industries. In the 1960s, these industries experienced a rapid decline in profitability as competition from the Far East countries became more intense. By the 1970s, shipbuilding and the meaningful employment it gave to thousands of men had almost completely disappeared from the region. New opportunities for employment were never successfully re-established in the area, and many of these men never worked again. If they did get jobs, they were often unskilled and seen as less meaningful than the jobs they had lost in shipbuilding.

At the same time as opportunities for employment were declining, major redevelopment of housing was taking place. Traditional tenement homes built in the 19th century were no longer adequate. They were often overcrowded and had poor sanitation. Outbreaks of infectious diseases were common. They were demolished and new, multi-storey flats were intended to replace them.

While this policy was intended to improve living conditions for residents, it had an adverse effect on social cohesion. People were rehoused often many miles from friends and relatives on whom they had relied for support for many years. Many of the newly developed areas were poorly planned and had poor access to schools, leisure and other amenities. The combination of joblessness, poverty and relative social isolation was soon followed by adverse effects on health and well-being and general resilience in the affected areas of Scotland. By the time I qualified as a surgeon, in the mid-1970s, the health of those living in the poorest areas of the city had deteriorated markedly.

A progressive increase in mortality among those at the lowest end of the socioeconomic scale saw a relative decline in life expectancy in the poor. The widening gap between rich and poor has continued to widen since the 1960s and by 2015, the richest 20% of Scots could expect to survive 10.5 years longer than the poorest 20% (1). This appears to be one of the widest gaps in life expectancy seen among European countries.

Why Scotland should have developed such wide health inequality has been a matter for considerable study over the years. Conventional explanations such as differences in the rate of smoking, quality of diet and uptake of exercise by social class certainly contribute to the problem and for many years were thought to be its principal cause. The usual health education approaches were used to try to encourage healthy habits, and they made little difference at a population level. The failure to persuade poor people to change health damaging-habits was no surprise. As a clinician working in a hospital serving one of the poorest parts of the country, I was very familiar with what was happening. People who feel life is not worth living are not interested in prolonging it by giving up habits such as smoking or drinking alcohol if those habits are their main source of contentment.

On many occasions, I would see patients who had been admitted to hospital with a problem associated with poor diet, alcohol or smoking. I would point out to them that failure to change their lifestyle would bring further serious health problems. The response was usually dismissive of such advice. "What do I care, doctor? What have I got to live for? Getting drunk is my main pleasure in life!" My clinical experience led me to conclude that just giving people struggling with chaotic lives information about the risks they were running was not the answer. They needed a reason to stay healthy if they were to take the decisions necessary to be healthy. In effect, they needed adequate supportive environments and coherent policies to acquire resilience to overcome the difficulties they encountered in daily life.

The American Psychological Association defines resilience as "the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress–such as family and relationship problems, serious health problems or workplace and financial stressors. It means 'bouncing back' from difficult experiences" (2). I learned that people who had lived most of their lives struggling unsuccessfully with these challenges often give up. This realization led me to conclude that the most effective way of helping these patients might not be merely by conventional health care but by building resilience to allow them to take control of their lives when faced with adversity. I became a public health doctor to try to gain an understanding of how health could be created in an economically challenged population.

The need to refocus thinking and practice

Medical training involves learning about pathogenesis – the processes that cause disease. As a result, doctors become focused on illness and gain little insight into the processes that create wellness. In its Constitution, WHO defines health as: "a state of complete physical, mental and social well-being and not merely the absence of illness or infirmity." Traditionally, health care systems, and the governments that pay for them, focus on the second part of that definition and pay less attention to achieving the state of complete well-being. It is hard to criticize governments for not paying attention to well-being. When health care systems are failing, everyone notices and government is criticized. However, few people understand how to create well-being in a society, so attention is drawn to health care as the main determinant of health. The public health community in Scotland has been working to enhance an understanding of the importance of creating well-being and the methods for doing so.

What causes a state of complete, physical, mental and social well-being? This is a question that has accompanied me throughout my professional life. A key aspect of current thinking is that people who maintain a sense of well-being have the mindset that allows them to manage daily life effectively, analysing its challenges and meeting those challenges successfully. They learn to cope with adverse events and are adaptable in dealing with them. They do this because they have a sense of purpose in their lives. Optimism is mentioned often as a feature of those who display high levels of well-being. People who display an optimistic outlook on life often do so because they feel in control of their circumstances and have a sense of purpose and meaning in their lives. As a result, they are confident in their ability to deal with problems. Another common feature of people who have a strong tendency to well-being is that they are surrounded by a supportive network of people who will provide advice and help at times of difficulty.

American sociologist Aaron Antonovsky introduced the concept of salutogenesis. Antonovsky advocated the study of the factors that support human health and well-being, rather than only factors that cause disease. His salutogenic model described how health and well-being emerged when individuals learned to see the events surrounding them as making sense, feeling that they had ability to cope with those events and having the conviction that that they could successfully manage them. Antonovsky described this concept of "a sense of coherence." Antonovsky suggested that failure to develop a sense of coherence would lead to a state of chronic stress (3).

The suggestion that chronic stress could be a consequence of the social circumstances in which one lived provided a means of investigating the biological consequences of social inequality. Extensive study has confirmed the link between social and economic adversity and stress. Undoubtedly, poverty can be associated with stress. When one cannot feed oneself, when families are threatened with losing their home because they cannot pay the rent, stress will be overwhelming. Individuals who have not developed a sense of being in control will be particularly affected by poverty. Other adverse outcomes such as domestic violence will be more common in families struggling with debt, and this situation has an impact on children's well-being.

However, it is important to note that poverty by itself does not necessarily lead to loss of resilience. One knows of people, often in one's own families, who made a success of their lives despite coming from a poor background. In most cases, as children, they will have experienced strong attachment through a nurturing family and had the experience of growing up in a safe and supportive community. Poverty is one of the many influences in a complex system which determines one's health outcomes.

Stress experienced in early life is particularly damaging to an individual's health and well-being outcomes. Important to the understanding of inequality in health and social outcomes is the issue of Adverse Childhood Experiences (ACEs). In 1995 a study was set up in California (United States of America) to follow the health of children as they grew up. The research had been prompted by the observation that many obese patients attending the hospital's weight management programme dropped out. The clinician in charge identified a history of abuse in many of the drop outs, and the study was set up to identify possible links between childhood experience and poor health and social outcomes as an adult. Twenty years later, the ACEs study has shown strong statistical associations between different forms of neglect, abuse and parental absence and adverse outcomes in health, education, employment and increased incidence of criminal convictions (4). Such observations take one back to the critical importance of ensuring support for families living in chaotic circumstances if one is to create a culture of well-being in modern society.

Decades of study gives insights into the mechanisms by which socioeconomic adversity produced health inequality, but finding solutions to the problem of inequality and its consequences proved elusive. Thus, the need to refocus thinking and practice is a real and urgent one. The conceptual framework of Health 2020, proposed by the WHO Regional Office for Europe in 2012, is a good step forward towards addressing such need (5).

Political and economic determinants

Scotland is still faced with the health consequences of social and economic chaos of the mid-20th century, but it seemed likely that the concepts of well-being such as those which underlie salutogenesis might explain widening inequality in mortality across society. More importantly, might it be possible to use it to find a way of narrowing the inequality gap?

Can one transform the lives of the disadvantaged? The answer to that question seems obvious. If they are poor, give them money. If they are disadvantaged, give them free health care and free education but surely the United Kingdom has had, for 70 years, a well-developed welfare state in which many of these needs are met. However, well-being involves much more than having access to services. Having a sense of purpose allows one to value oneself, and thus more likely to make positive decisions that enhance well-being. Feeling safe and feeling confident that one has access to support when needed are some of the many elements of a supportive environment. As maintained in Health 2020, supportive environments are key for strengthening individual and community resilience (5).

What mechanisms do most societies have to support well-being and resilience in those at the lowest end of the socioeconomic scale? It became obvious that the welfare provision available to those at the lower end of the social scale in Scotland was not working at the level required to make a significant change in terms of population well-being and reduction of health inequities.

Why the welfare state in the United Kingdom has not prevented the problem

In the first half of the 20th century, a network of charities, churches and volunteer organizations mainly provided welfare in the United Kingdom. These organizations were far from effective. In 1908, a Labour Member of Parliament commented: "Here in a country rich beyond description there are people poor beyond description." The polarization of society between rich and poor caused concern that civic unrest might emerge. In 1911, the Government of United Kingdom created a national insurance scheme which funded a means tested pension for those over the age of 70. In the late 1940s, the idea of the welfare state was extended so that every worker contributed to a scheme of national insurance. Money was deducted from the weekly pay packet to build up a fund to pay out benefits to those who were sick or unemployed. The scheme would pay pensions at the end of a working life to employees and the self-employed. The idea was to support families living in poverty. Benefits were to be set at a level that enabled a man, his wife and child to survive. Most of these benefits were universal. Everyone had a right to it based on contributions. Only if additional help was needed was a means test used.

In addition to providing financial security for all, free health care, through creation of the National Health Service, and free education became universal. These were funded from taxation and were free at the point of use. Since taxation was the source of funding for these services, wealthy taxpayers contributed more to their costs, thereby supporting social cohesion.

The welfare state provided care for everyone – the aim was protection from cradle to grave. However, by the latter decades of the 20th century, problems began to emerge. Increasing cost and demand for services and unwillingness of governments to increase taxes to pay for them led to increasing debate about the sustainability of the welfare state. Eventually, in the 1970s, Margaret Thatcher's government wanted to reduce public spending and so diminish the role of the state in supporting those in difficulty. There was an increase in private provision of health and social services. The Tony Blair government wanted to ensure efficiency and management accountability for service delivery. They introduced management techniques such as targets and league tables which were introduced as a means of pushing up standards. Citizens became consumers and service users and were expected to choose which services suited them best as a means of introducing markets into the system. The lines between public and private sectors became blurred, and services provided by the private sector received public funding.

Public services, in an effort to cut cost and meet targets, became more focused on delivering services using protocols and guidelines rather than meeting the needs of the citizen. The ageing population, as well as the longer term consequences of economic difficulties of the past decade, have undermined the capacity of many individuals and families to be well and feel safe and in control of their lives. Yet, public agencies seem less interested in supporting people to take control of their lives than meeting process and financial targets. The welfare state in the United Kingdom cannot therefore tackle the inequality that has widened over the past decades. It is less well able to support those individuals and now often ends up making their problems worse. Thus, the opportunities for building resilience and promoting health and well-being are therefore heavily dependent on these political, cultural and economic drivers.

The Scottish context

In 1999, many of the responsibilities of government in Scotland were handed over to the newly established Scottish Parliament. Scotland developed its first working legislature in the 13th century. However, in 1707, it was decided that the Parliament of Scotland should be unified with that in London, and the Scottish Parliament was dissolved. In 1997, after a referendum in Scotland, a new legislative body was established in Edinburgh. The new body took responsibility for health, education, social work, housing and criminal and civil law. In fact, the Parliament became responsible for many of the aspects of life that determine well-being. One of the first decisions made by the newly elected Labour government in Scotland was to abolish the internal market in health care. The management of health care was to remain in public service hands.

Over the next few years, various efforts were made to support conventional health improvement interventions with smoking, diet, exercise and alcohol campaigns and interventions. However, few were found to have made any significant impact on narrowing inequality.

In 2007, an election returned the Scottish National Party to power. The new government began to look closely at the issues underlying inequality. It established a commission to review how public services might work differently to tackle inequality (6). The Christie Commission reported in 2011 and recognized that inequality in all its dimensions was the most important issue facing Scottish society. Several of its recommendations were particularly relevant to the concepts of well-being in both individuals and in communities. It recommended that the Scottish Government should:

- recognize that effective services must be designed with and for people and communities – not delivered top down for administrative convenience;
- maximize scarce resources by utilizing all available resources from the public, private and third sectors, individuals, groups and communities;
- work closely with individuals and communities to understand their needs, maximize talents and resources, support self-reliance and build resilience;
- prioritize preventative measures to reduce demand and lessen inequalities;
- identify and target the underlying causes of intergenerational deprivation and low aspiration; and
- make greater investment in the people who deliver services through enhanced workforce development and effective leadership.

In order to achieve these recommendations, the Commission suggested that the Government should have four objectives in mind. These were:

- a decisive shift towards prevention;
- greater integration of public services at a local level driven by better partnership, collaboration and effective local delivery;
- greater investment in the people who deliver services through enhanced workforce development and effective leadership; and
- a sharp focus on improving performance, through greater transparency, innovation and use of digital technology.

Reaction to the report was mixed. Political parties welcomed the focus on prevention. Voluntary organizations welcomed the focus on involving people and providing support for those in need. The media, predictably, were critical. Although the report laid out a plan for change, there was agreement across commentators that it had failed to describe the methods and processes that would be necessary for real change.

Six years on, the comments of the media seem to have been accurate. There have been some changes, mainly affecting structure. Public services have been reorganized. Some aspects of health and social care were already integrated. However, no real progress on the issues affecting socially marginalized communities appears to have been achieved. Why? Basically, the comments of the media are correct. The report had good intentions but no method for delivery. This is a problem that many policy-makers have encountered. They see a problem, but the method for tackling the problem eludes them. As it happens, at the same time the

Christie Commission was reporting, the National Health Service in Scotland was engaged on transformational change in hospitals using many of the principles of prevention outlined in the Christie Report.

The Scottish Patient Safety Programme was implemented in 2008. Its original aim was to improve care in Scottish hospitals by improving the safety and reliability of health and social care. It did so with a focus on preventing harmful incidents, by bringing together different disciplines to work in the problems, and it used the frontline staff who delivered the care to innovate by designing and testing the interventions. In short, it used the four principles contained in the report of the Christie Commission. In applying this method for improvement, standardized mortality rates in Scottish hospitals fell substantially. The frontline staff tested ways of improving outcome and, when they worked, the effective interventions were scaled up across the whole National Health System. How did they achieve this transformation? They did so by accepting that hospital care could not be changed using deterministic cause and effect methods. Care delivery is complex, and methods for transforming complex systems were required.

Lessons learnt and way forward

I would like to conclude this testimony by outlining a number of strategic issues. Hopefully, these final personal reflections can help to advance the thinking and innovate practice for strengthening individual, community and system resilience. These levels of resilience are crucial for better population health and well-being outcomes and the reduction of health inequities.

Seeing health as an emergent outcome of a complex system

The study of pathology teaches doctors that diseases have causes. Find the cause, and one can prevent or treat the disease. This cause and effect model does not apply to well-being and resilience. Well-being is created by the interaction between many different influences. In part, it is due to the absence of disease, but it is largely determined by the interaction between the individual and many aspects of the physical and social environment across the life-course. In technical terms, this means that health is an emergent property of a complex system.

A complex system is one in which many elements interact with each other. A feature of such a system is that it is difficult to predict how its different elements might interact to produce a particular outcome. It is also difficult to infer cause and effect because the different parts do not interact linearly. One can never be sure if any particular action will have the desired outcome because of the modifying effects of all the other parts of the system. Efforts to change the system can, therefore, result in unanticipated outcomes.

Methods for changing complex systems

Traditional studies of the type used to evaluate the effectiveness of a single health intervention focus on the cause and effect relationship between the treatment and the outcome. Such methods would be unable to produce a conclusive result if applied to a complex system. This realization requires the use of alternative methods to study change in such systems. Improvement science is the term applied to the study and use of methods and techniques for improving processes and outcomes in any system. The type of improvement approach used in Scotland has been the improvement collaborative.

A collaboration to improve patient safety was started with the Institute for Healthcare Improvement in the United States of America. Details of the progress of this collaborative can be found online (7).

The aim was to reduce hospital mortality by 15% by 2015. Staff were asked to engage in a series of small tests of the changes which seemed likely to lead to improvement over a short period of time. As these small tests were successfully implemented, the learning was shared across the National Health System, scaling up the changes. Continuous measurement of the impact of the changes being made motivates staff as they see success. Certain questions are asked in this process.

- What is one trying to accomplish?
- How will one know that a change is an improvement?
- What changes can one make that will result in improvement?

Staff then employ Plan-Do-Study-Act cycles for small, rapid-cycle tests of change. The Institute for Healthcare Improvement calls this the Model for Improvement in all of its improvement efforts (7).

Collaboratives bring together groups of professionals to work together to gain understanding of the processes and practices they use in delivering interventions to people. Staff from many organizations get together to share ideas, test those ideas and implement those that work to produce a desired change in outcome. This pattern of activity is an example of transformative resilience (8). The Institute for Healthcare Improvement used this approach to enhance patient safety in hospitals. It was applied in Scotland, and significant reductions in mortality rates followed. The Scottish experience of improvement science suggested it might be an effective way of moving the complex system which underlies socioeconomic inequalities.

Understanding the problem of inequalities

The most common causes of death are heart disease, stroke and a variety of cancers. Any strategy aimed at narrowing health inequalities would surely involve reducing the risk of these conditions across the population. However, deaths from these conditions usually occur in later life, and it became clear that narrowing the gap in mortality from cancers occurring in old age would have a relatively minor impact on life expectancy. What were the real drivers of inequality?

A study of the pattern of mortality across the socioeconomic spectrum and how it varied across the life-course showed that the widest inequality in death rate occurred in young people. Specifically, the gap was widest in the 20–45 age range, and driving the inequality were deaths due to drugs, alcohol, suicide, violence and accidents. These deaths cannot be attributed to smoking, poor diet or lack of exercise. They are, however, socially determined and may well be linked to the social disintegration seen in Scotland in the latter decades of the 20th century. If so, efforts to create well-being, by supporting a sense of control and purpose in young people, might provide a framework for narrowing the gap.

The conventional approaches used up until now have not been successful in creating large-scale improvements. If one is to improve health and well-being, one needs to consider how complex systems work to produce well-being.

The creation of well-being – the problem and its possible solution

If the evidence supports the idea that citizens who feel in control of their lives and who have a sense of purpose are more likely to make good choices, develop a high level of resilience and be well, then a welfare system that undermines control needs reforming. There are a number of examples of interventions successfully enhancing control and transforming lives.

The importance of early life in creating this set of positive mental attributes has already been mentioned. The deep emotional bond that forms between mother and child allows the child to feel safe and secure. The sense of security allows the child to develop intellectually and socially. Failed attachment is associated with educational failure and increased aggression. Consistent parenting allows children to develop a sense of control over the world around them and is associated with the characteristics identified as supporting a sense of well-being.

In 2012, these improvement methods were applied to socially determined problems, and a collaborative approach to child health was created. Through frontline staff getting together regularly to share ideas and test them in different settings, a number of significant developments have been seen. Since establishing the Early Years Collaborative, there has been a 15% reduction in stillbirths in Scotland. Income of poor families has increased as a result of health care staff supporting access to financial advice. Mothers recovering from substance abuse have been supported to change their lifestyle resulting in improved birth weights. Children from areas of deprivation have been reported to have higher literacy and numeracy skills. These are some of the outcomes seen as a result of the application of improvement approaches to the complex system that creates well-being and resilience in children.

Scaling up efforts to tackle inequality in Scotland

My experience over the past two decades leads me to conclude that the greatest challenge in the coming years is to extend this approach to adults living difficult, chaotic lives. Socioeconomic inequality in Scotland is a principal driver of inequality in life expectancy and a range of other outcomes such as education, criminal convictions and unemployment. An understanding of complex system behaviour indicates that conventional cause and effect approaches are unlikely to be successful. A collaborative approach is needed which involves public sector agencies acting to support people to develop resilient behaviour in different ways. Collecting data on the effectiveness of such efforts of support will allow processes that work to be identified and scaled up across Scotland.

Observation over many years of successful transformation carried out by small, locally driven projects convinces me that trust and friendship between citizens and those helping them are an essential first step. To help people effectively, the public sector worker needs to take certain action.

First, build a relationship with all citizens and see the problems from their perspective. Ask "What matters to you?" This takes time, but it builds trust and allows the real issues that are causing anxiety in the citizen to be identified. Instead of telling citizens what they need, ask them to explain what is causing them most stress.

Second, work with citizens to identify and design a solution to their concerns. By helping them work through the issues, whether debt, poor housing or employment, citizens learn that solutions are possible and begin to feel a sense of efficacy.

Third, make expert advice available to the worker. Whether the people trying to help the citizen are nurses, social workers, housing officers or police officers, it is inevitable that they will come across problems outside of their expertise. Services must be coordinated to allow this to happen. Places that have tried this approach, however, indicate that the need to pull in experts is relatively uncommon.

Having a sense of trust in the services designed to help citizens will be a new experience for the chaotic citizens who is used to so-called experts telling them what they need, a bureaucracy that requires numerous forms to be filled in and an organization that cares more about its performance indicators and its costs than it does about caring for people.

My journey in trying to understand inequality and the lack of control that leads to it convinces me that, by applying this approach and using integrated data sets to collect and analyse the outcome of these interactions, politicians can be given an insight into new ways on tackling inequality. The old, deterministic approach which sees health inequalities as being due to diet and smoking, educational inequalities as being due to differences in schools, and inequalities in criminal behaviour as being similarly explainable by bad behaviour, will no longer suffice. A new relationship between people in difficulty and those detailed by society to help them is required in Scotland. Making the right change happen for individuals will not only improve their resilience and well-being but will also enhance community resilience as they learn to provide support for each other.

The journey continues.

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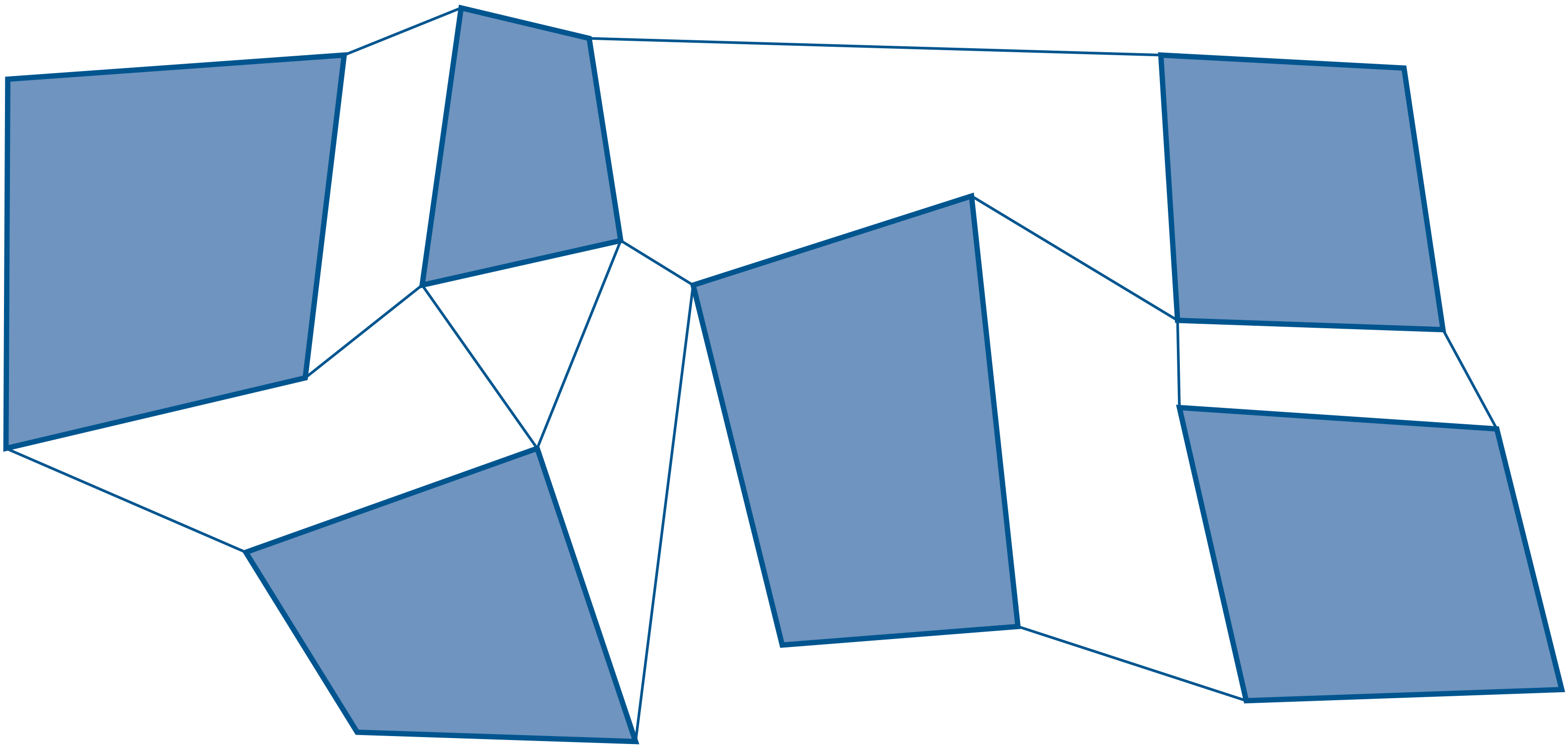
Part 2. Building resilience by developing and sustaining partnerships between institutions and communities

Strengthening resilience and developing supportive environments for population health and well-being is key for effective practices in curative, rehabilitative, preventive and health-promotive actions undertaken by health systems and public health programmes. Resilience strengthening is an integral part of person-centred care, as defined by WHO. It requires a rather radical reconfiguration of all aspects of health service planning and delivery. The inspirational examples presented in Part 2 show that health-related personnel, patients and their families, civil societies and social organizations, such as self-help and mutual health groups, are partners in the co-production of health, well-being and resilience building.



Austria. Innovative practices in strengthening patient and community resilience and building a people-centred health system: the Lienz experience

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Abstract

This inspirational example shows how self-help groups hosted within the local hospital in East Tyrol, Austria, are a critical resilience factor to support individuals coping with ill-health. Over 50 self-help groups, managed by supportive lay people and encouraged by hospital staff, extend the type of comprehensive care and resilience-building processes that individuals affected by health problems need. The resilience-building approach is built on a partnership between lay initiatives and professional health resources. The strong network of self-help groups aids patients and their families to see their health condition as a challenge that can be overcome and managed, rather than an insurmountable problem.

Issue

Self-help or mutual aid is a process of voluntarily sharing common concerns. It is based on reciprocal support, information exchange, coping skills, empathy and resilience building. Self-help is about building supportive environments to enable people to have more control over their health and better cope with adversities. As such, mutual and self-help represents a basic element in a process that aims to strengthen individual and community resilience (1).

The WHO Health Promotion Glossary explains that self and mutual help relate to actions taken by lay persons to mobilize resources in a process that aims to promote, maintain or restore the health of individuals or communities (2). In Health 2020, the role of voluntary organizations and self-help groups is clearly acknowledged, regarding the “working with civil society” strategy for its implementation (3).

Mutual or self-help includes a wide range of formats and processes, such as face-to-face, on-line and telephone interactions, and pen pal exchanges and networks. Focus may vary from issues related to population age-groups to specific health topics or challenges. All these modalities of work are in the inspirational example that follows.

With the increase of the burden of noncommunicable chronic and degenerative diseases, the issue of self-help and the need to ensure that people gain control over their health and life circumstances have become even more apparent (4–6). Population groups representing a strong tradition of self-help in Europe are senior citizens, the disabled and youth. In recent years, mutual aid groups have expanded to cover migrants and other groups at risk of vulnerability and isolation. Self-help groups are part of a strategy to cope with health challenges associated with a wide range of problems: abuse, addictions, bereavement, caregiving, ageing, disability, eating disorders, unemployment, heart disease, mental disorders and many other conditions such as arthritis, cancer and HIV/AIDS.

The benefits of participating in self-help or mutual support groups are numerous, and their contribution to well-being and resilience has been documented by scientific literature for at least five decades (7–10). For example, scientific studies show that people involved in mental health self-help groups are hospitalized far less than people in comparable situations who are not involved in these programmes. Studies have also reported that people who actively participate in mutual and self-help groups keep their jobs more than those who do not participate. Participants tend to better manage family ties, live more independently and assume more responsibility in coping with the impact of their health challenges (11). Other studies have shown that effective mutual and self-help groups contribute to higher self-esteem and higher confidence of recovery (12,13).

Self-help groups provide a social support system, especially in conditions that isolate people. People benefit from communicating with others who are experiencing the same feelings, and this generates empathy and resilience (14). Extensive scientific literature exists in the field of mutual help and resilience, mainly in the area of mental health, but also covering different chronic conditions such as cardiovascular diseases, cancer and the effects of bereavement (15,16).

A review of the effects of support groups on people with early-stage dementia and mild cognitive impairment revealed that participants and care partners who accepted this help experienced, inter alia, positive impacts on performance and satisfaction of meaningful activity, resilience, self-help and care partner coping self-efficacy (17). Another study showed that an open group mutual aid model was an acceptable and helpful method to facilitate recovery after an acute cardiac event. The model was facilitated by a social worker and an occupational therapist, as part of a secondary prevention and cardiac rehabilitation programme (18).

A systematic review of peer-support programmes for people with cancer indicated a high level of satisfaction with this kind of programme, whereas evidence for psychosocial benefits was mixed. In particular, one-on-one, face-to-face, and group Internet peer-support programmes were the most effective (19). Based on a multivariate analysis, school-aged children with cancer who reported higher family function and positive relationships with friends showed higher resilience than their counterparts (20). According to a pilot study from Germany, resilience should also be considered as a protective psychosocial factor for patients after stem cell transplantation for neoplasms of blood origin (leukaemia, lymphoma, myeloma, aplastic anaemia) as high-resilience patients reported less anxiety and depression, higher physical, emotional and social functioning, and a better quality of life than low-resilience patients (21). Research has looked at people with cancer and showed that they can benefit from self-help groups by regaining mental well-being, developing supportive relationships and participating in collective activities. Cancer patients also have the opportunity to see other members redefine their identity, not as victims, but as people with a purpose in life (22).

The Lienz self-help experience offers new insights about effective cooperation between lay initiatives and health services that contributes to patient and local community resilience.

Action

This example from Lienz, a small town in East Tyrol, Austria, demonstrates several points. First, self-help can go hand in hand and take advantage of a supportive environment provided by the local hospital and other community assets. Second, developing and nurturing local lay resources for people facing health problems and their impact on life circumstances are possible. Third, health services can facilitate and value these lay resources. Lienz Hospital makes available space for self-help groups to meet, and its staff is available if and when self-help groups require their input. Thus, the supportive environment provided by Lienz Hospital, combined with other local resources, enables patients and their families to expand their capabilities and develop resilience. Furthermore, participants develop a positive feeling that they are not left alone to address the many physiological, psychological, financial and other everyday challenges posed by the health problems they face.

The strong network of mutual and self-help assistance available to individuals in East Tyrol provides both a direct support and a buffer against adverse life events. It has become a much valued local resource for enhancing the quality of life and resilience of not only patients and their families but also the entire community. The self-help groups hosted within the premises of Lienz Hospital have developed over time and include a wide range of actions for emotional support, information sharing and the provision of material resources and services. Participation in Lienz self-help groups has been reported to reduce isolation, create a sense of community and connectedness, enhance self-esteem, improve problem solving and help to develop coping skills. Self-help groups in Lienz are not a replacement for – or an alternative to – existing hospital and primary care services. These groups complement and provide additional value to treatment protocols, rehabilitation processes and health promotion programmes.


© Lienz Hospital

Lienz Hospital in East Tyrol, Austria.


© Selbsthilfe Tirol

Members of Selbsthilfe Tirol provide information on self-help groups in Lienz Hospital, East Tyrol, Austria.

These innovative practices in strengthening patient empowerment and resilience, and developing supportive environments for patient health and well-being are part of building a people-centred health system (23).

To better appreciate the action undertaken in developing these groups, understanding the context in which this development occurred is necessary. The Lienz District (Bezirk Lienz) is in the south-eastern part of Tyrol (East Tyrol). More than 50% of the area is 2000 metres above sea level, and only 8% of the surface is usable. East Tyrol has a population of approximately 48 000 inhabitants with a life expectancy of 80.04 years for men and 85.87 for women (ranked fifth in Austria). According to a regional survey on well-being (including 11 topics) by the Organisation for Economic Co-operation and Development (OECD), the entire region of Tyrol received 8.5/10 points in health, which puts the region first out of nine regions in Austria. Compared across all OECD regions, Tyrol is in the top 21% in health. The mortality rate is 7.0 deaths per 1000 people, and average life expectancy is 82.2 years (24).

The District Hospital of Bezirk Lienz comprises 13 departments with a total of 372 beds and more than 800 employees (about 110 doctors) and is the site of the association of 33 municipalities. The District Hospital is officially recognized as a Breast Care Centre, a Baby-Friendly Hospital and more recently, has been awarded a certificate as a Self-help Friendly Hospital.

Self-help Friendly Hospitals aim to formalize the current cooperation between self-help groups and the hospital. Representatives of self-support groups and hospitals in Hamburg, Germany, developed this designation (25), which is described in German language scientific literature (26–28). The main elements of Self-help Friendly Hospitals are to:

- inform patients about the opportunity to participate in self-help groups;
- train and encourage health professionals to appreciate and cooperate with self-support groups;
- involve patients and their knowledge in the hospital's quality management;
- organize public relation activities jointly with patient self-help groups; and
- provide infrastructure and space for self-support groups within the hospital premises to facilitate meetings and training activities and to promptly act upon requests of the self-help groups (26-29).

The umbrella association of self-support groups in Tyrol, "Selbsthilfe Tirol", provided the Self-help Friendly Hospital accreditation in Tyrol. The accreditation process and the audits are supported by the faculty of the Nonprofit, Social & Health Care Management Programme at the Management Center Innsbruck. The accreditation certificate states that

> *self-help groups play an important part in creating a communication bridge between the hospital and the patients. This programme forms the basis of an open communication platform, where patients are able to openly exchange their experiences and to foster personal feedback.*

The accreditation is awarded based on the following admission criteria and a number of standards regarding the cooperation between patient self-support groups and the hospital.

1. The hospital provides meeting room infrastructure for self-support group activities.
2. The hospital actively informs patients about self-support groups.

3. The hospital provides information on self-support group activities on its website and in informational materials in waiting areas.
4. Cooperation exists between support groups and the hospital.
5. Cooperation exists between the hospital and self-support groups in public and media relation activities.
6. The hospital and its departments provide patient-support group coordinators.
7. A regular exchange of experiences takes place between hospital staff and self-support groups.
8. The hospital provides further education for health professionals in patient self-support groups.
9. Self-support group representatives participate in the hospital's quality management activities.
10. The cooperation between the hospital and the patient self-support groups is formally documented in an agreement between the umbrella organization and the hospital.

A detailed description of the accreditation requirements is in the audit report for the Self-help Friendly Hospital in Lienz (30).

Lienz Hospital hosts the local branch of Self-help East Tyrol, which was established in 2002 with six groups. The branch has grown dramatically in recent years reaching a total of 55 groups in 2017. The main objective of this umbrella association is to inform local communities on disease prevention measures and health promotion opportunities. Support is provided through actions that aim to strengthen patient and community resilience in tackling health challenges and adverse conditions. Support also includes providing psychosocial assistance in the everyday life management of people with various disabilities and patients coping with chronic degenerative diseases. Self-help groups in East Tyrol address conditions such as breast cancer, prostate cancer, multiple sclerosis, genetic disorders, eating disorders, depression and other psychiatric conditions, Alzheimer's disease, dementia and other neurological conditions, miscarriages, abortion and stillbirth, diabetes and cardiovascular diseases. These services are available to bereaved family members, informal caregivers and many others.

Several activities provide support.

- Training is provided for group leaders, self-help group members and target groups such as caregivers.
- Public awareness is raised by:
  - means of conferences on specific topics, and organization of health and self-help days;
  - an information stand located in the entrance area of the hospital announcing talks on various topics to inform the local communities and schoolchildren;
  - Kontakt-Café, a meeting place to exchange experiences, discuss new ideas or contact the self-help group;
  - publication of a quarterly magazine, called "INTERN";
  - regular update of a dedicated web page on Selbsthilfe Tirol's website (www.selbsthilfe-osttirol.at);

- supporting networks (network meetings, meetings of self-help group leaders, excursions and Christmas party for group members);
- information and counselling to patients by healthcare professionals; and
- fundraising events.

Another important factor for the success of the project is cooperation with a wide range of local resources such as: the health workforce and staff of Lienz Hospital; nursing homes and home care organizations; the Red Cross, Caritas and welfare agencies; local communities; the faculty of the Nonprofit, Social & Health Care Management Programme at the Management Center Innsbruck; the chamber of commerce and local firms; health insurance companies; schools and other public institutions; cross-border partners and associations; local authorities; and regional and national organizations (Health Austria GmbH, Austrian Self-help Association (ARGE)).

Impact

The results of interviews conducted during research fieldwork in June 2016 confirm most of the benefits that people obtain from participating in self-help groups and are amply documented in the scientific literature. Table 2.1 summarizes the main benefits mentioned by members of Lienz's self-help groups.

Table 2.1. Main benefits of participating in self-help groups in Lienz, East Tyrol

Benefits	Description
Empowerment	Participating in a mutual or self-help group helps patients to develop skills and know-how helpful to address the many implications of their health problem and gain more control over their everyday life.
Negotiation skills	Actively participating in a self-help group improves confidence so patients can better negotiate services and care that fit their strengths, weaknesses and personal choices.
Self-image and esteem	People in self-help groups tend to feel better about themselves than those not involved. Their decision to engage in self-help instills confidence in family members and others.
Self-awareness	Self-help tends to increase patients' self-awareness capabilities. Members of mutual and self-help groups are usually better equipped to recognize potential problems and handle them before they become unmanageable.
Time saving	Pursuing self-help allows a patient time to address a variety of additional needs.
Inexpensive	Self-help is generally free of cost. Modern online technology such as Skype and other devices allow patients living in rural and isolated areas to benefit from self-help despite their geographical isolation.

As mentioned before, the three pillars underpinning the Lienz strategy to empower patients and make them more resilient to a chronic disease or other adverse conditions are to:

1. inform the local communities on prevention measures and health promotion actions;
2. provide psychosocial assistance in day-to-day life management and allow people to share information on patient experiences and share solutions; and
3. utilize the expertise and competence of doctors, nurses and staff of Lienz Hospital for advice and further support.

One of the elements of the experience in East Tyrol is the strong and effective relationship between the local health workforce (Lienz Hospital doctors and nurses) and the patients and their self-help groups. In other words, patients and their families can easily meet members of self-help groups within Lienz Hospital, talk about their own experiences and sustain each other. They can tap into knowledge, information and advice readily available by health professionals that support the self-help network.

Another important means of support is the availability of information for patients, their families and the general population. Brochures and information sheets developed by various self-help groups, the publication of a quarterly magazine, and an informative and regularly updated website provide information about group meetings and events, self-help federations in Austria and information on other useful networks and publications.

In addition, to raise public awareness, self-help lectures are held in schools, at Leinz Hospital and other community settings. Many events are open to the public and include fairs, health events and lectures, self-help days and various forms of entertainment. In addition, an efficient administration, responsible for the annual budget and creating new groups as needed, facilitates the daily work of the 55 self-help groups.

This cooperative approach is unique in Austria and represents one of the key factors for the success of the Lienz self-help experience. Room for further development and improvements exist; for example, some of the professionals interviewed suggested that having a psychologist attached to some groups would be advisable. This is especially true for groups with cancer patients, as doctors and nurses are not necessarily trained to address some of the complex emotional and psychological issues that patients may experience.

Most people interviewed emphasized the good cooperation between the education sector, local communities, nursing homes, the Red Cross and other regional and national health organizations, and local authorities, some of whom would like to strengthen their links with the self-help groups and further engage civil society in support activities. In contrast, many people interviewed mentioned that general practitioners were still sceptical about the effectiveness of these self-help groups in terms of disease prevention, treatment and rehabilitation. Several people interviewed mentioned that general practitioners were not very cooperative and/or even feared that support groups may greatly influence decisions concerning the planning and management of health care, diminishing their own role. Similarly, interviewees felt that research institutions could play a greater role. With a few notable exceptions – the Management Center Innsbruck, and some researchers at the Austrian Health Institute (ÖBIG) and the Department of Sociology at the University of Vienna – university institutions do not seem particularly interested in projects/studies with self-help groups. Reversing this would surely increase the data and evidence on the work and impact of self-help groups.

The main findings of the research fieldwork carried out in Lienz are summarized in a strengths, weaknesses, opportunities and threats (SWOT) analysis (Fig. 2.1).

Fig. 2.1. SWOT analysis of self-help groups, Lienz Hospital.

Strengths	Weaknesses
• Information on disease prevention and health promotion, and advice for patients • Good relations between patients and Lienz Hospital's staff • Training for self-help group members/leaders • Availability of hospital premises for self-help group meetings • Good relations with teachers' association • Collaboration with local authorities and media • Cooperation with different segments of society and regional/national health organizations • Good and transparent administration • Updated information on website, magazine (social networks) • Organization of self-help events all year round • Accreditation as Self-help Friendly Hospital	• Lack of evaluation systems • No comparison with other initiatives of this kind • Lack of a strategy/vision for the future • Lack of visibility outside the hospital setting • Long-term sustainability • Difficult interaction with university institutions caused by the remote location of East Tyrol and the distance to university cities

Opportunities	Threats
• Self-help groups act as a bridge between local authorities/political institutions and health and social services. • Self-help groups are an effective means to collect patients' needs and advocate for them in relevant committees. • Make the Lienz initiative in East Tyrol visible and share it with other European regions. • Publicize that the Lienz initiative is a resource not only for health services but also for the whole East Tyrol region.	• Scepticism by some general practitioners • Lack of a critical mass of people outside the health sector supporting the self-help groups

Lessons learnt

This subsection outlines the lessons learnt with some reflections for future development of local action to strengthen community resilience.

First, a system is needed to evaluate the impact and work quality of the self-help groups and to identify further improvements. The SWOT analysis summarizes the strengths that make the Lienz self-help experience an inspirational example in empowering patients and strengthening their resilience. Nevertheless, most self-help group leaders recognize the need for an evaluation system to better assess the quality of their interventions and what needs to be changed or ameliorated.

Second, raising awareness in the general population is crucial; self-help groups are an important tool to increase resilience when people experience a difficult phase of their life or have a chronic condition. Activities should concentrate more on health or health promotion in addition to the more traditional single disease focus. Further initiatives should focus on providing services, particularly in remote mountainous areas especially for some psychiatric patients that ideally should be visited in their homes and not in a hospital setting. A systematic plan is needed to sustain or increase the involvement of schoolchildren and younger generations. The plan should aim to attract more men as these groups are mostly attended by women. Efforts should be made to change the perception of many general practitioners that still undervalue the role of self-help groups. This could be effectively pursued within the current commitments for the future Austrian primary care centres and networks (31).

Third, there is a need to collaborate with researchers in primary care, in social and political sciences, education, communication, and organizational innovation and development to better document what has been achieved. Leaders of self-help groups indicate that this engagement is critical in order to scientifically document the benefits patients receive from support groups which is an indispensable element of people-centred health systems. This would also help self-help groups in East Tyrol to become more innovative for the benefit of patients and their families.

Finally, future initiatives should be identified and implemented to further strengthen the link and collaboration with local authorities. The aim is to position the extensive network of self-help groups in East Tyrol as a primary resource for the resilience of not only patients but also local communities. This overall vision could address various elements of the future development of the network of self-help groups, including fundraising, and other matters related to increasing the quality and sustainability of the present and future plans of the network. This point is timely as the network has increased in number and memberships and is ready for its next phase of development.

The network could take advantage of several opportunities over the coming years. One is to engage and nurture a critical mass of people operating in different sectors of society (not just the health sector) in support of self-help groups. From advocacy to support, the positioning of self-help groups as a key element of the quality of life and sustainable development of East Tyrol is vital. In this next phase of development, there is a great opportunity for Lienz's self-help initiative to become more visible not only in East Tyrol but also in Austria and beyond.

Acknowledgments

This narrative is based on research fieldwork carried out by the authors in Lienz during the summer of 2016, and subsequent information gathering and analysis in 2017 and 2018. The fieldwork was facilitated locally by Ms Helene Brunner, Head of Administration of Lienz Hospital. During the fieldwork, over 50 people were interviewed including board members of the self-help organization Selbsthilfe Osttirol. Many professionals working at Lienz Hospital were also interviewed, such as the medical director; the chief head of nursing; group leaders; the heads of the departments of urology, psychiatry, neurology, and internal medicine; the heads of nursing gynaecology and day unit, and of nursing neurology. In addition, a meeting was arranged with local politicians and members of civil society who are engaged to strengthen cooperation with self-help organizations to promote resilience. This helped to better understand the context in which the strong network of self-help has developed in East Tyrol and the challenges and new opportunities they have.

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Finland. New therapeutic approach for schizophrenia that strengthens resilience and saves one million euros per year

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Abstract

In 2011 the Department of Psychiatry in Peijas Hospital (city of Vantaa in the metropolitan area of Finland's capital city Helsinki) started a new approach to promote the resilience of schizophrenia patients through the Fenix project (1–3). Out of 10 patients who started the programme in 2011, five have already regained their ability to work and are employed. The need for hospital-based in-patient care among all patients has diminished significantly, and their resilience has increased. In addition to improving the conditions of patients, the new therapeutic regime has brought financial savings of almost 1 million euros per year.

Issue

Schizophrenia is a severe mental disorder characterized by distortions in thinking, perception, emotions, language, sense of self and behaviour. More than 21 million people worldwide are affected. It is associated with considerable disability and may affect educational and occupational performance. In addition, people with schizophrenia are 2–2.5 times more likely to die prematurely than the general population, due to concomitant illnesses such as cardiovascular, metabolic and infectious diseases (4). Schizophrenia is a treatable condition, and treatment with medicines and psychosocial support is effective. The engagement of family members and the wider community in providing support is crucial (5).

WHO's Mental Health Gap Action Programme (mhGAP), launched in 2008, uses evidence-based technical guidance, tools and training packages to scale up services for mental, neurological and substance use disorders in 80 countries worldwide. It asserts that with proper care, psychosocial assistance and medication, tens of millions of people could be treated for depression, schizophrenia and epilepsy. Appropriate treatment can prevent patients from committing suicide and help them to lead normal lives (6).

WHO's Mental Health Action Plan 2013–2020, endorsed by the World Health Assembly in 2013, highlights the steps required to provide appropriate services for people with mental disorders including schizophrenia. A key recommendation of the Action Plan is to shift services from institutions to the community (7). Mental disorders are one of the top public health challenges in the WHO European Region, from the point of view of prevalence, burden of disease and disability and affects about 25% of the population every year. The WHO Regional Office for Europe has therefore developed the European Mental Health Action Plan which focuses on seven interlinked objectives and proposes effective actions to strengthen mental health and well-being. Investing in mental health is essential for the sustainability of health and socioeconomic policies in the European Region. The European Mental Health Action Plan corresponds to the four priority areas of the European policy framework for health and well-being, Health 2020, and is designed to contribute to its implementation (8).

Schizophrenia causes a heavy financial burden to patients and society. In a report presented in 2010 to the European Brain Council, which included all member countries of the European

Union plus Iceland, Norway and Switzerland covering a total population of 514 million, the total annual cost of psychotic disorders are estimated to be about 93.9 billion euros (9,10). Additionally, indirect expenses are caused by the time spent in in-patient hospital care, inability to complete an education, difficulties in finding and maintaining gainful employment, problems in physical health due to lifestyle (unhealthy diet, lack of physical activity, smoking, alcohol and substance abuse, etc.) and family dependence. In Finland, the expenses caused by schizophrenia has been estimated to be about 700–800 million euros per year (11). Presently, instead of stationary inpatient care, best practices in psychiatry recommend ambulatory treatment, which is more humane and also less expensive.

Action

The Fenix team of schizophrenia patients at Peijas Hospital started in 2011. The driving force to initiate this project was to improve the quality of life of mentally ill patients with poor adherence to treatment (12). Additionally, the project was motivated also by the desire to reduce health care costs. The planners of the Fenix project were inspired by the positive practical experiences of The Center of Excellence for Relapse Prevention (CERP) in Munich, Germany (13).

The CERP programme is an initiative of psychiatrists around the world, who are committed to improving the treatment offered to people with psychotic disorders, focusing particularly on the issue of relapse prevention, i.e. preventing the return of psychotic attacks. The programme consists of a series of educational meetings hosted by recognized centres of excellence in psychiatry. The objective is to provide a forum for education and information sharing around the topics of relapse and relapse prevention. Meetings are held at centres of expertise that are role models in terms of their development and provision of relapse prevention services.

The Fenix project adopted the CERP methodology in Peijas Hospital based on scientific evidence emphasizing the role of therapeutic alliance in schizophrenia treatment (14–16). The challenge of therapy for schizophrenia patients, both in Finland and abroad, has been poor compliance in ambulatory care, especially in the use of antipsychotic medications. The goal of this new model was to strengthen patient adherence to prescribed medication regimens in ambulatory care and hence prevent the exacerbation of psychosis leading to repeated hospitalizations.

A group of patients adopted the project title Fenix from Greek mythology. Phoenixes are birds reborn from their own ashes, always appearing when someone is in great need of help. From the beginning, the group has been focused on resilience building. Professionals and patients meet weekly using a format characterized by equality and familiarity/informality, and without the stereotypical hierarchy usually associated with their roles. Together, the group plans the agenda for upcoming sessions. They discuss the symptoms of their disease and the everyday challenges they face. The process is facilitated by the development of a friendly environment which allows relaxed exchanges among patients and hospital staff and entails having coffee/ tea together, outdoors activities and other informal gatherings and events.

The project was launched with a minimum budget. The aims were to meet participants with a new attitude, to change their situation through positive feedback and to strengthen their resilience. Initially, one of the group's wishes was to prepare meals together, and one day Dr Marcelo Chiramberro, Feeniks Project Coordinator at Peijas Hospital, brought a pasta machine to the group session.

> *The delicious smell of pasta sauce in the winter of 2012 marked the beginning of the Fenix project. The group has its own coffee machine, in which patients can choose from a variety of different types of coffee, from a caffè-latte to a ristretto. This sight can mean something simple for people who do not have this disease, but for these patients, it means making a decision, which a lot of them find difficult. This small operation through education and exercise can be extrapolated to making major decisions and building daily routine plans. It's also important to relate to familiar faces and time-tables as incentives. Regular attendance is acknowledged with a small present. The group members keep regular contact through email and mobile phone, not forgetting celebrations. The project provides a more equal and transparent treatment plan to diminish the stigma that is still today connected with mental disorders.*

Dr Marcelo Chiramberro, Feeniks Project Coordinator, Peijas Hospital

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From left, Fenix project group members: Ms Heli Väisänen, Ms Katja Sarkkinen, Ms Marita Leiponen, Ms Jenna Ilvonen, Dr Marcelo Chiramberro, Mr Matias Hyytiäinen, Ms Ira Hynninen-Sundelin and Ms Kaisa Palonen.

Impact

The outcome has been promising. Eighteen months from the beginning of the project, eight of 10 group members did not need hospitalization. After six years, five of the 10 initial patients are gainfully employed, and none have needed hospitalization. As a result of this project, both treatment costs and general health costs of patients have been reduced. What matters most is the improvement in the quality of life of these patients who return to social reintegration, leaving behind the stigma and marginalization that often exacerbate these types of diseases. Patients improve their ability to relate to their environment and improve self-esteem and resilience. They create bonds of friendship with people who face the same difficulties, improving their capacity for self-help and help towards others. Many of these patients have little or no social contact. Social isolation, loss of affective bonds and abandonment of medication are factors that contribute to poor disease management. This frequently causes loss of functional capacity, cognitive deterioration, increased violence, high risk of suicide, etc. (6).

Psycho-educational interventions such as those provided through the Fenix project, coupled with pharmacological and psychological treatments, demonstrate clearly observable modifications and outcomes in patients. Many patients had previously lost family ties. The social return and improvement in patient autonomy significantly reduces the pressure on family members and can improve familial relationships (17).

In 2015, the Fenix team launched an art project, creating paintings, photographs and felt textiles. The final outcome of this one-year creative activity was presented at an art exhibition – TOWARDS THE LIGHT – in the Peijas Hospital lobby in November–December 2016. Through this project, patients related to their environment through creative individual and group art expressions. In 2015, the Finnish Nursing Association awarded the "For the Wellbeing of People" prize to the Peijas Fenix project.

Through this approach, interventions like Fenix not only decrease the symptoms of illness in a particular person, but also positively impact the family nucleus, society and the health system by providing better quality care and reducing cost. This outcome gives solid evidence of the strengthened resilience among the group's members.

Lessons learnt

The Fenix project had to overcome a number of barriers. There was low treatment adherence, and some physicians and nurses were initially sceptical. Arguments favoured a paternalistic model of treatment (the physician decides alone without involving the patient) as more effective than involving patients as a constructive partner in the treatment plan. The project has demonstrated that a partnership between patients and health care professionals improves patient compliance to treatments and quality of life.

Another hindrance was the limited financial resources to implement the project. The therapeutic team relied on imagination and enthusiasm, and demonstrated improved quality of life and lower health care costs without the benefit of additional resources.

The project has proven to be sustainable. Encouraged by the good results in strengthening resilience and improving health and well-being outcomes of its members, two similar groups were started in psychiatric outpatient facilities in 2015. These two groups are located in the ambulatory centres of Peijas Hospital in the east and west regions of the city of Vantaa, and are satellites of the Fenix group. They follow the same operational model and involve patients with poor adherence to treatment, limited knowledge of their disease and repeated hospitalizations due to relapses.

This project is an example of a bottom-up, grassroots effort that was easy to start and easy to replicate. It required minimal resources both in development and maintenance. It is anticipated that additional Fenix projects will be implemented in other municipalities as word of its success spreads.

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Italy. Strengthening resilience in hospitalized children: the approach of Meyer Children's Hospital

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Abstract

Florence's Meyer Children's Hospital is a world-renowned centre of excellence for treating complex and life-threatening diseases. In addition to its clinical reputation, it is increasingly known for its holistic approach to cure, care, rehabilitate and promote children's health and well-being. It takes a holistic approach to both its hospitalized children and the health and well-being of their parents and siblings. Hospitalization can be a traumatic experience for children and their families. This inspirational example describes support that Meyer Children's Hospital has put in place and activities integrated into its clinical work to strengthen the resilience of its young patients and their families. The Meyer approach has inspired the design and delivery of services in a way that is empowering for those in need. As such, Meyer has become a resource for resilience, health and well-being and its influence reaches far beyond the walls of its clinical institution.

Issue

The hospitalization of a child or adolescent affects patients and families throughout many dimensions: emotional, relational, social and in some cases, financial. Experiences vary depending on the young patient's age, stage of development and diagnosis, as well as the social and cultural contexts. Children may be concerned about being separated from their loved ones during a long-term hospital stay. Hospitalized children may fear pain or wonder what is going to happen to them. They may be worried about their bodies not functioning properly or being different from other children while hospitalized or once discharged. Reduced contacts with their social network of friends and limited participation in education, sports and leisure activities are also sources of stress for hospitalized children (1–3).

Altered school attendance and separation from peers may result in problems related to school outcomes and to a deep sense of isolation and failure due to difficulties in creating and maintaining friendships (4–11). This is even more relevant for adolescents, who are at a crucial developmental stage in which they need to be independent from their parents and build their own identity, maintain a strong peer group and live in a safe environment. Hospitalization leads to the risk of being placed in a context that affects their privacy and independence-building process while isolating them from their peer group (12,13). The lack of privacy is the most frequent and dominant aspect reported by teenagers during a long hospital stay. They value the availability of some private time to maintain relations, as in the case of a phone call, or easy access to emails and other means that allow them to be in contact with their peer network (14–18).

A child's hospitalization is also an extremely stressful event for parents for several reasons. Quite understandably, when faced with their child's serious or life-threatening health problems, they may experience anxiety, apprehension, fear, loneliness, hopelessness and depression. Further stress may occur due to other aspects such as disruption of family routine, separation of family members and discontinuity in the child's education and structure of everyday life. Organizational and economic difficulties can also generate stress, especially in families who are forced to move away from home to ensure that their sick children receive appropriate treatment (19). International scientific literature shows that protracted health treatments have a significant economic impact on families, representing an important stress factor that can aggravate parental emotional and mental health and, potentially, child well-being (20).

Numerous studies indicate that siblings are also subjected to significant stress caused by the disease and hospitalization of their brothers or sisters. This stress is related to both concern about the ill child and the organizational disruption caused by altering the family's routine. For example, the daily relational structure can undergo change when one or both parents are obliged to spend time far from home to be near the hospitalized child or in cases when the entire family moves. In these cases, siblings and friends can also be uprooted from their social, friendship and scholastic contexts, and this can indeed be a source of high stress and anxiety.

It is not uncommon for sick children and their siblings (and sometimes their closest friends) to show symptoms of anxiety, depression, post-traumatic stress, lower quality of life and lower school performance and social functioning (21–24). For the hospitalized child, reducted school attendance can cause a sense of isolation and the worry of falling behind classmates in terms of academic achievement, as well as the risk of having to repeat the school year and losing current classmates and established relations (25–28).

Caregivers are essential for the care and well-being of the hospitalized child. Indeed, parents are the primary agents involved in children's direct care and play a fundamental role in providing a variety of protective and supporting factors that influence their well-being (29). The perception of stress by parents is influenced by the degree of engagement in some of the activities offered to hospitalized children to make them feel they are in control of their life. Such activities include school services and the possibility to be in contact with their schoolmates. Considering the importance of education in a child's life, the possibility to continue school activities help hospitalized children and caregivers to feel less pressure. Parents whose children used school services and other educational activities describe themselves as less irritable and as having a higher degree of emotional control compared to other caregivers (28).

Action

This subsection gives an account of the main actions that characterize the Meyer's approach to strengthening resilience in hospitalized children and their families. Despite the challenges, the stressful impact of hospitalization can be significantly attenuated. All the aforementioned risks can be avoided or minimized by an approach that considers the hospitalized child in a holistic way. This is the principle on which Meyer bases its overall mission, organization and actions. The goal is to address the clinical and non-clinical needs of its young patients from all perspectives. In addition to treating and rehabilitating children, one of the aims is to free them and their family from the additional stressors outlined above.

Meyer is a teaching hospital associated with the University of Florence that is part of the Tuscan Regional Health Service and is a centre of excellence for the treatment of children with serious health problems. All of its efforts are dedicated to ensuring that its young patients receive the highest quality health care, as well as to supporting patients and families during a challenging phase of their lives.

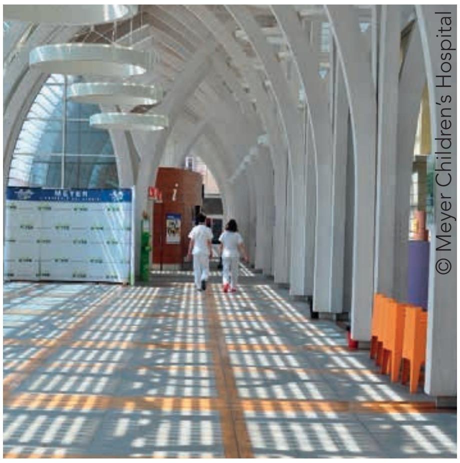
Meyer Children's Hospital, Florence, Italy.

Founded in 1891, it was among the first institutions in Europe to be completely dedicated to paediatric care. Over the years, it has become an international point of reference equipped with all paediatric medical and surgical specialties. Meyer's team of professionals performs clinical, training and research activities in an integrated way, and works to incorporate innovations into priority health care needs. About 1300 professionals work at Meyer Children's Hospital, including approximately 300 doctors, 600 nurses and 30 psychologists, physiotherapists and other health professionals. It offers 247 beds and manages over 44 400 cases in the emergency room yearly. In 2016, 8762 ordinary admissions and 24 515 day cases were carried out. Outpatient activity continues an upward trend and exceeded 685 000 services. Meyer was recently tasked by the regional government with reorganizing and coordinating Tuscany's regional paediatric network.

The approach and the action taken by Meyer are captured by the phrase "from potential stress to receiving resilience and well-being." In addition to excellent health care, hospitalized children and their families can rely on a network of parent and volunteer associations linked to Meyer that contributes to making the hospital environment warm and reassuring. The Meyer Children's Hospital community counts on the active support of the Meyer Foundation, which collects and channels the donations of many individuals, companies and associations into projects and initiatives supporting the well-being of children and their families. Meyer works to integrate the contributions into a holistic vision that focuses on all aspects of the treatment, care, rehabilitation and healing processes for hospitalized children and their families.

This vision is translated into Meyer's overall mission and actions, and also incorporates the use of modern technologies with research activity and new therapies to achieve high levels of health care in a context of humanization, empathy and resilience building. In line with Article 7 of the European Association for Children in Hospital Charter, Meyer believes that children should have the "full opportunity for play, recreation and education suited to their age and condition and shall be in an environment designed, furnished, staffed and equipped to meet their needs" (30).

The Meyer structure is based on the concept of therapeutic architecture, which provides a warm and reassuring feeling to the child upon entering Meyer. Entering a hospital's premises is usually the first stress factor in a child's hospitalization experience. A glazed pergola, designed to mimic winds through the park that surrounds it, creates a sense of calm, warmth and beauty that makes a positive impact on the psychological well-being of young patients and their relatives. It leads to the main hall which was inspired by the ribs of the great whale in the story of Pinocchio and recreates an ethereal atmosphere. Created in this child-friendly environment is an area dedicated to teenagers that aims to respond to their need for privacy and integration with peers.



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The main hall of Meyer Children's Hospital, Florence, Italy, is inspired by the ribs of the great whale in the story of Pinocchio.

One way in which Meyer works to satisfy patient needs is through play therapy activities. Storytellers, clowns, musicians and pet therapy animals are often present on the wards and in common areas, and a dedicated playroom and library are open every day. Meyer has about 750 active volunteers who are typically available from 09:00 to 20:00. Families may request additional support (for example, parents who need to work or assist their other children). In 2017, almost 2000 additional hours were granted to address these types of special needs. Such activities provide a much-needed break in the daily routine of the hospital where, due to specialized care, many children (and their families) must remain for long periods.

Cases treated at Meyer have a high degree of complexity, with an average diagnosis-related group weight of discharged patients of 1.19 in 2016. Meyer attracts patients from other regions, with 26.5% of patients coming from outside Tuscany, and therefore far from home. These families may feel stress due to their distance from their home environment in addition to the stress related to their child's disease. A long hospitalization can lead to increasing emotional and financial burdens due to the patient's potential separation from family members. The Meyer Foundation has developed agreements with institutions and associations to serve hospitalized children and minimize stress. This has resulted in a strong hosting network that guarantees free hospitality to the families who need it most and live far from Meyer. This service meets the needs of the family, taking into account the length of stay and the therapeutic indications in the case of discharged children who must stay in Florence for additional treatments. In 2017, 644 families received such support, with an average time spent in the accommodation facility of 15 months.

Migrant families have a longer residence time in these facilities, on average 2–3 years. In 2016, over 50% of the chronic patients in Meyer's home care service were migrants. First, the migrant family receives direct support; then individual support is offered to help integrate the family and increase autonomy, by taking a longer view, even after treatment ends. Examples of this support are helping families to find a home and fostering relationships with institutions that provide services necessary for their daily life. The Hospital Social Service, in collaboration with the resources of the volunteer sector, associations, parishes and the Catholic organization

Caritas deals with a wide range of practical daily life aspects. Volunteers offer assistance by accompanying parents to the employment office, setting up professional training courses, and providing support and cultural mediation in dealing with a variety of bureaucratic immigration issues.

Families in economic difficulty received 222 meal vouchers to Meyer's cafeteria and an offer for a continuous supply of food throughout 2017. One source of significant anxiety is the complicated process to request and receive disability benefits. In 2017, over 100 families were supported in this important process.

For children with complex conditions and/or disabilities who have been hospitalized for a long time, returning to life outside the hospital can be particularly critical and stressful. To facilitate this transition, Meyer, on a biweekly basis, provides space for parents and children outside its premises. Thus, the child can be gradually included in a peer group in a safe manner while parents can meet other adults outside the context of their child's illness.

© Meyer Children's Hospital

Entrance to the primary school at Meyer Children's Hospital, Florence, Italy.

In order to facilitate the resilience of patients and their families as they cope with problems related to long-term care at Meyer, an internal hospital school was established in 2005 that guarantees children's right to education and educational continuity. This school bridges the gap between Meyer and the hospitalized children's home schools, enabling them to be in contact with their schoolmates. This approach contributes to children feeling more in control of their life. It facilitates a better recovery and the process of readapting to the school environment after discharge, reducing anxiety about missing school, being held back a year and being further separated from friends and familiar environments (31).

When a child first arrives at Meyer, teachers and doctors meet with the parents to introduce them to the school and other initiatives. The teachers working at Meyer provide both primary and secondary education, and come from 22 schools in Florence, as well as other cities throughout Tuscany. The regional educational authorities have implemented a policy in support of the programme that recognizes the working hours of teachers at Meyer. Many volunteers – often retired teachers – are also an active part of this network. This important work allows gaps to be filled and hospitalized students to be supported with methods that traditional educational institutions cannot provide.

Impact

Despite the many ways of assessing the variety of activities that characterize Meyer's approach to strengthening resilience, this example focuses on Meyer's educational activities and related support measures that reduce the stress and anxiety of hospitalized children and their families.

Dr Alberto Zanobini, Chief Executive Officer of Meyer Children's Hospital, explains the Hospital's approach:

> *We consider the hospital school to be an essential and protective part of the treatment of children and adolescents. School lessons and learning in the hospital, also with the help of technological aids that promote a connection with the home class, feed faith in a positive and desirable future. This helps hospitalized children and their families to bounce back and regain control over their life despite the very shocking and worrying time they have to go through. I think that our approach is made possible because, over the years, we have been able to foster and sustain a 'health alliance' between our hospital work and many public institutions and the non-profit volunteer sector.*

According to the teachers, the most important skill for this special support is flexibility. Flexibility, along with the pursuit of personalized support action, is needed because the profiles of each child vary widely from one case to another. Furthermore, classes may often be interrupted as a result of the child's health and treatment schedules. In this context, teachers working at Meyer must find a flexible approach to overcoming the traditional rigidity of the school system. The content and pace of each school class is adapted to each child's specific needs. Depending on the situation, even the location of the classes is fluid; teachers may go to a child's bedside or the child may go to a classroom within Meyer Children's Hospital.

One primary school teacher describes her experience working at Meyer:

> *When I began working with these children, I gave myself some objectives. It was clear that the first priority goal was to improve the life of each student by promoting their state of well-being. I was thinking how to offer them an appropriate service that responded to their hospital treatment needs, while respecting their interests and aspirations and ensuring an uninterrupted learning and personal growth process. In the last two years, I have designed individualized paths for each student in agreement with their parents. This includes the importance for children to stay in contact with their home school. In pursuing this, I interface with other educational colleagues and professionals such as psychologists, medical doctors and nurses that work at Meyer. I have seen first-hand how the service that we offer, which is tailored to each child, is part of his or her overall treatment and healing process. In addition to being important from an educational point of view, it really helps attenuate and overcome the sense of isolation that hospitalized children often experience. I do believe we help them to regain control of their life and increase their resilience in accepting, adapting, coping and managing the impact of their disease. I guess we contribute to their right of having a 'normal' life during their stay at Meyer Children's Hospital.*

As a testimonial to the success of this approach, all school examinations taken at Meyer are recognized by the regional educational authorities. This allows children to have a smooth transition when they are discharged from the hospital and resume their studies at their home schools. The success of this school initiative, combined with other support activities offered by Meyer, can also be evidenced by the appreciation of students and parents. A mother of a middle school child on the oncology ward offers her perspective:

> *My son had a wonderful relationship with his teachers and learned to make the best of his difficult situation. He also learned little by little to explain and share what and how he was feeling. The school's friendly environment and the encounters with the teachers stimulated profound and meaningful dialogue that helped him to externalize his inner sentiments, which was helpful as he really missed his class and friends a lot.*

A parent of a first grade student had this experience:

> *The teacher was able to calibrate the lessons based on how my son was feeling. In some circumstances, the teacher helped him to work actively when he was able to, while in others the teacher read to him when his physical state kept him from concentrating. I saw that he was able to keep up with his classmates and that this was very important for him. He felt that he didn't fall behind because of his medical conditions and he was able to somehow continue getting on with his life in a normal way.*

Sometimes, even in the terrible moment of the loss of one's child, what was done for him when he was alive can be of consolation for parents. The following letter was written by the parents of a child who died of cancer at age 11, after excelling during his year at the hospital middle school.

> *Dear teachers, as you know, our son has become a little angel. We have faced this year together with you, with so much hope and strength...but the Lord wanted him by his side. Our grief is excruciating and there is no consolation. We are very grateful for what you have done for our son, accompanying him in his studies with great competence and sweetness. Thanks to you he realized his great desire not to lose the school year and he succeeded with great difficulties between one therapy and another. Your memory will remain indelible within us. We thank you from the heart."*

The benefits of this network of schools are not only educational but also health related. Regular meetings are held between teachers, doctors, health assistants, psychologists, social workers, library operators and the families of hospitalized young patients. Besides discussing and reporting on the educational development of the child, teachers are an excellent source of information for doctors, as they are in a privileged position to observe a child's health and well-being outside the hospital medical context, while still being inside its walls.

The model is innovative in many respects and has allowed Meyer to respond to an evolution in practices over the years, some of which have been key in reducing the length of hospital stay in favour of increased care in the comfort of the child's home. This flexible approach allows the educational service to be provided to children both during hospitalization and at home, thanks to the significant commitment of the teachers.

Since 2005, hundreds of students have attended the hospital school. Demand for educational services is increasing, with approximately 890 patients participating from 2012 to today. During the 2016/2017 school year, 110 elementary school students, 64 middle school students and 42 high school students attended hospital school. In addition, 51 children aged 3–5 years have been taught by primary school teachers; and a kindergarten section has been requested.

A spin-off programme – "Me too!" – was also created for patients' siblings. The illness of one child often changes the life of the entire family; for example, leaving home to be closer to the hospitalized child, which disrupts normal life and school attendance. In order to bolster the capability of the entire family to cope successfully and minimize stress, the "Me too!" programme provides support and school integration to the patients' siblings. In addition to providing the hospital school and the at-home hospital school, Meyer also works to include both siblings and the patient after discharge in the local school, with the belief that the school is the main institution for the real inclusion and integration of the family into the social fabric.

Lessons learnt

First, all the actions to improve global care and reduce additional stressors for children and families have been possible thanks to an integrated organizational effort among several actors, both institutional and non-institutional. Much thought and energy needs to be devoted to nurture the many available resources (both institutional and lay) that make the Meyer's approach to resilience sustainable. Nurturing available resources and making their use sustainable in the long term is a key lesson for this strategic work and for other children's hospitals that want to adopt a similar approach.

Second, having in place a process that systematically fosters cooperation and integration of efforts is essential. Hospital staff, volunteers, patient associations, civil society and the Meyer Foundation work in close collaboration, based on common values that are explicitly expressed in their respective statutes, missions and way of working.

Third, creating a supportive environment where everyone is able to contribute to strengthening resilience and promoting health and well-being without hierarchical, professional or other barriers is necessary. In the Meyer approach, everyone contributes according to his or her own expertise. This has enabled a process in which professionals and volunteers working directly with children and families establish a close synergy with the Meyer Children's Hospital leadership on organizational aspects, and with the Meyer Foundation for financial support and coordination of activities. This coherent and shared effort does work and makes a difference in strengthening resilience of hospitalized children and their families.

Acknowledgments

The authors thank the following professionals of Meyer Children's Hospital for their invaluable contribution: Dr Donatella Accolla, Dr Luigi Sirianni, Mrs Laura Mori, Mrs Maddalena Turco, Dr Flaviana Tondi and all of Meyer's primary school and middle school teachers.

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Kyrgyzstan. Strengthening resilience in rural communities

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Abstract

The Community Action for Health (CAH) programme in Kyrgyzstan is a partnership for health promotion between the government health system and village health committees (VHCs). It began in 2002 with a pilot project in one rayon and is now a countrywide programme involving some 1700 VHCs that cover 84% of all villages. VHCs are independent civil–society organizations that work to improve the health literacy of the population and empower communities to address local determinants of health at the village level.

The CAH programme, endorsed by the Ministry of Health, has been part of health reform programmes (Manas Taalimi and Den Sooluk) since 2005. For World Health Day 2018, WHO documented the Kyrgyz experience in a video (1). It is a powerful example of how to use local assets for disease prevention and health promotion to improve resilience. It is an effective approach for sparsely populated rural areas to bring health care and health promotion closer to the whole community with practical steps towards universal health coverage.

Issue

"The population lacks knowledge about health…" is a standard formulation in many discussions about health in Kyrgyzstan. The CAH programme aimed to address and improve this weakness in the population by increasing health literacy and empowerment. The programme's main goals are:

- to empower VHCs to improve health in villages
- to enable the government health system to work in partnership with VHCs.

VHCs are community-based organizations that engage in voluntary activities aimed at improving the health and resilience of their communities. They collaborate with the government health system and local self-government structures. They are organized into 58 rayon health committees, which are registered as non-profit organizations. Rayon health committees in turn form the national Association of VHCs, which represents the interests of VHCs in their dealings with the Ministry of Health and donors, and is the contractual agency for this cooperation.

In each oblast, the CAH programme begins by analysing the health priorities of the people in all villages, facilitated by primary health care staff. This is done in neighbourhood groups and with tools designed according to the principles of participatory reflection and action[5] and involves 50–70% of households. During this analysis, participants elect people from their neighbourhoods as candidates for the VHC. These bottom-up elections tend to produce new kinds of leaders, who enjoy the trust of their neighbours and are active and community-minded. The board of the VHC is elected from among these candidates at a village meeting.

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[5] This was formerly known as a participatory rural appraisal.

Health Promotion Unit[6] staff then work with VHCs in two ways. They build their organizational capacity to help them become independent civil–society organizations, and they train them to implement health actions in their villages to address the health problems identified as priorities by their communities, as well as other public health issues.

Health actions cover a broad range of issues drawn from the analysis of communities' priorities and from additional public health priorities. The Republican Centre for Health Promotion designs and implements health actions in collaboration with the agency financing them. Health promotion units support and train VHCs to implement the health actions (2). VHCs then visit people in their homes to discuss health issues using information materials and tools. VHCs involve members of the school parliament[7] in all health actions and cooperate with other organizations as appropriate (local primary care providers, local self-government structures, veterinary services, etc.). VHC members receive no remuneration for time spent on these health actions. In addition, the Republican Centre for Health Promotion, with support of the CAH programme and partners, such as the Swiss Agency for Development and Cooperation, has developed a school health education programme approved by the Ministry of Education. It focuses on five issues: brucellosis, personal hygiene, dental hygiene, tobacco use, and sexual and reproductive health. An example of the work and impact of VCHs in addressing the problem of brucellosis is in the next subsection.

Brucellosis

The incidence of human brucellosis in Kyrgyzstan increased dramatically after 2000 and by the mid-2000s, it had one of the highest incidences in the world. The underlying epidemic among animals had been spiralling out of control due to the use of an ineffective Brucella vaccine (S19) on sheep and goats. In addition, more families were in close contact with these animals now than during the time of the former Soviet Union when veterinary professionals addressed this disease. Most people did not know how to protect themselves from infection by animals. Thus, brucellosis was identified as a top health priority in most oblasts during the initial participatory reflection and action analysis.

As most brucellosis cases occurred in boys and young men between the ages of 13 and 35 and around the time of the lambing season, it soon became clear that infections were mostly linked to lambing. The health action therefore focused on protecting people when assisting ewes with lambing. VHCs promoted 4 measures:

- use gloves
- have a separate lambing place
- use disinfectant (lime)
- bury animal placentas in the ground.

Every autumn before lambing season, VHCs explained these protective measures to people using information materials, and school parliament members went door to door to offer help with digging holes to bury animal placentas. The health action began in Naryn oblast in 2003 and was implemented in more oblasts each year as the CAH programme expanded.

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[6] A health promotion unit is a new structure with two people per rayon to promote collaboration between the village level and the rayon level.

[7] School parliament is an elected student body in all Kyrgyz schools.

VHCs also set up brucellosis committees made up of members of the local self-government structures, local health care providers, the veterinary service and the police. Their task was to organize the regular testing of all cows for brucellosis and to make sure that animals which tested positive were slaughtered and not secretly sold.


© Swiss Agency for Development and Cooperation

Using disinfectant after lambing in Kyrgyzstan.

When the veterinary service introduced an effective Brucella vaccine (Rev-1) from 2009 onward, VHCs discontinued these activities and instead helped to inform people about the new vaccination programme. However, as part of the school health education programme (developed by the CAH programme, Swiss Agency for Development and Cooperation and the Republican Centre for Health Promotion), school students continue to learn how to protect themselves against brucellosis before every lambing season.

Impact

In all oblasts, VHC surveys revealed substantial improvements in all four measures, especially during the first 2–3 years. Fig. 2.2 and 2.3 show the results of Batken and Naryn oblasts. Oblasts where the health action was implemented later (Batken) serve as a control group; their low baseline data demonstrate that the changes are the result of the VHCs' work (for example, compare the 2007 data for Batken and Naryn).

The impact of the intervention can be seen by the effect that VHCs had on the human brucellosis epidemic.

The results of oblasts that used the VHC interventions were compared with eight rayons in the south of Kyrgyzstan that serve as a control because no VHCs were there before the vaccination scheme began with Rev-1 (six rayons of Jalalabad oblast and two rayons of Osh oblast).[8] Fig. 2.4 shows that in both areas, with VHCs and without VHCs, the human incidence rate rose in parallel until 2006. Starting in 2007, the incidence in areas with VHCs stopped rising and started to fall in 2008. At the same time, the incidence rate in areas without VHCs continued to

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[8] The six rayons in Jalalabad are Ak-Suy, Ala-Buka, Susak, Togyz-Toroy, Toktogul, and Chatkal; VHCs were formed in 2012 and 2013. The two rayons in Osh are Alay and Chong-Alay; VHCs were formed in 2011, but because the brucellosis health action was always implemented in the autumn, the work of these VHCs could only affect case numbers in 2012. The total population of these eight rayons is about 700 000. Areas with VHCs comprise the country's six other oblasts plus two rayons of Jalalabad where VHCs existed from 2007 (Kara-Kulja and Nooken). Both areas include data for villages and rayon centres. Excluded from the comparison are oblast centres and towns in both areas.

rise dramatically until 2011, when the Rev-1 animal vaccine was implemented in the southern oblasts, resulting in a *drastic* fall in the number of cases in the following year, 2012.

Fig. 2.2. Four indicators of brucellosis prophylaxis in homes with sheep, goats and cows, villages of Naryn oblast

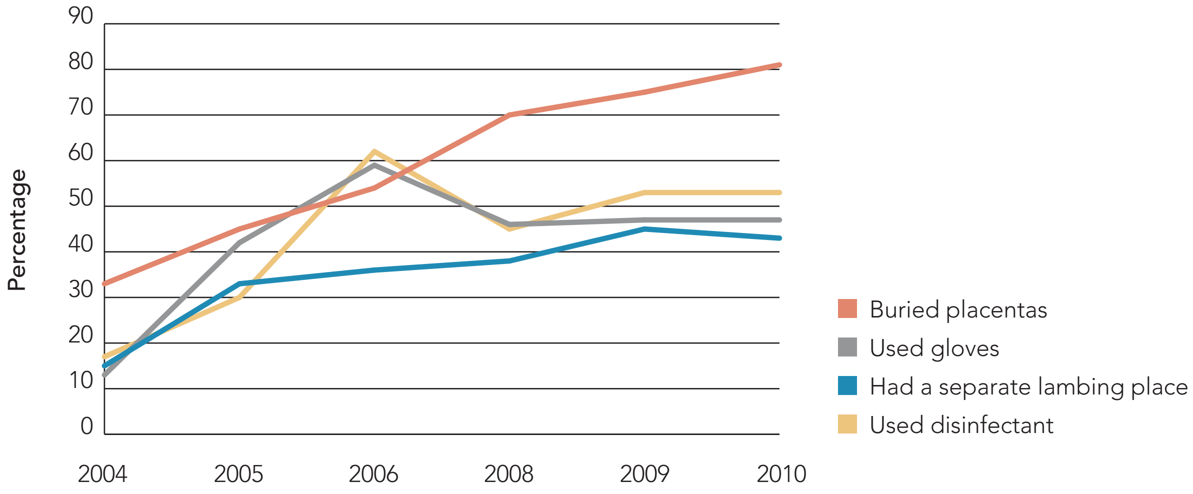
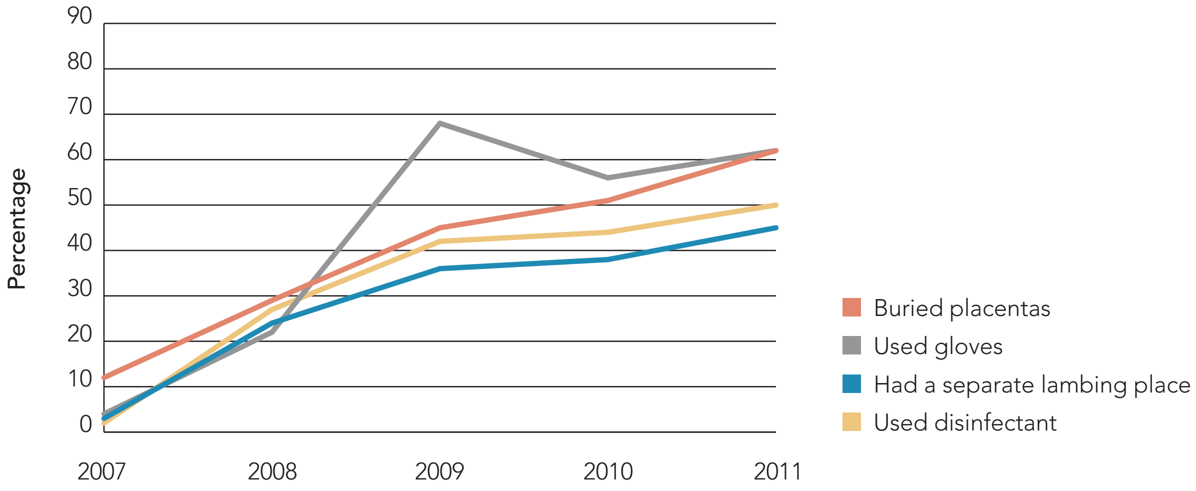


Fig. 2.3. Four indicators of brucellosis prophylaxis in homes with sheep, goats and cows, villages of Batken oblast



The decrease in the human incidence rate in VHC areas occurred before the vaccination of animals with Rev-1 began in the northern oblasts.[9] The dotted line in Fig. 2.4 shows that the seroprevalence in animals continued to rise until 2009 and only started to fall after the Rev-1 vaccination began. It is all the more astonishing that the human incidence rate began to decrease in VHC areas despite the further rising of the epidemic among sheep and goats.

These findings strongly suggest that as more VHCs participated in this health action between 2003 and 2010, their work caused the reversal of the human incidence rate in VHC areas from 2007 to 2008. The turning point is likely explained by the fact that in 2007, the area covered by VHCs almost tripled as compared to 2006.

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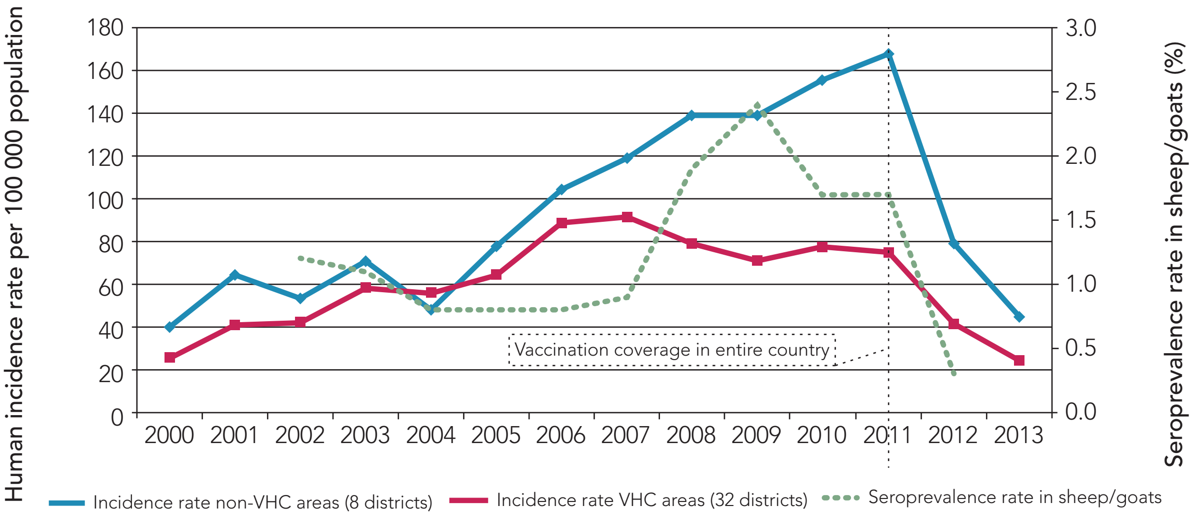
[9] Vaccination expansion: 2009 Naryn oblast (0.1 million animals), 2010 Issyk-kul and Chui oblasts (2.6 million animals), 2011 Talas, Osh, Jalalabad and Batken oblasts (12.3 million animals)

Fig. 2.4. Brucellosis incidence rate in areas with and without VHCs



The Swiss Tropical and Public Health Institute estimated that 10 192 cases of brucellosis were prevented in the VHC areas from 2007 to 2011. The costs saved were calculated to be US$ 4 827 065. Of this, the public health system saved US$ 646 393; patients saved US$ 2 788 889 in treatment and transportation costs and US$ 1 391 784 for loss of income.[10] The costs for the brucellosis health action were about US$ 300 000 over 10 years (for information material and training of VHCs on the health action and on organizational development). This was an investment of US$ 29.4 per averted case versus avoided costs of US$ 474, resulting in a cost-savings ratio of 1:16.

To sum up, evidence suggests that the CAH programme resulted in measurable health gains. The work of VHCs reversed the brucellosis epidemic in Kyrgyzstan long before an effective veterinary vaccine was introduced. The VHCs screened over two million people for hypertension during the period 2011–2016 and detected high blood pressure in more than 428 670 people, including 115 122 who were not aware of their condition. The action undertaken by VHCs has increased awareness of nutrition and led to early detection of health problems in children and pregnant women. The work of VHCs has also been instrumental in detecting early signs and symptoms of tuberculosis. It raised school-aged students' health-related knowledge on a wide range of issues including HIV/AIDS prevention. It improved health and well-being in villages through numerous initiatives addressing local determinants of health. It also gave women a platform to take on new roles in community management. Table 2.2 shows the status of the CAH programme as of 2017.

The CAH programme contributed to a decline in mortality through improved health awareness and behaviour. It is supported by the Ministry of Health and collaborating donor agencies. The Ministry of Health finances yearly training for three health actions (current focus is on early detection of health problems in children and pregnant women, nutrition in pregnancy and early childhood, and hypertension), and the annual assessment and planning exercise of the VHCs. A project funded by the Swiss Agency for Development and Cooperation and implemented

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[10] Unpublished commnunication by Joldoshbek Kasymbekov/Jakob Zinsstag (Swiss Tropitcal and Public Health Institute). Assumptions for the calculations were based on information from the Republican Clinical Infectious Diseases Hospital and on a survey of 95 brucellosis patients. According to these sources, the cost for the public health system of one human case was US$ 63, and the private cost for a patient was US$ 274 for treatment and transport. Loss of income was US$ 137 per case. The total costs per case therefore were US$ 474. It was assumed that 50% of patients were treated in hospitals and that 30% become chronic cases with an average treatment duration of three years.

by the Swiss Red Cross initiated the programme, supported its expansion throughout the country and financed numerous health actions.

Table 2.2. Status of CAH programme per oblast in Kyrgyzstan, December 2017

Oblast	No. of villages in oblast	Villages with VHCs	No. of VHCs	No. of rayon health committees
Batken	204	179	197	7
Chui	337	250	284	10
Issyk-kul	167	167	174	5
Jalalabad	374	356	425	15
Naryn	144	122	123	5
Osh	470	345	371	12
Talas	90	86	95	4
Total	**1786**	**1505**	**1669**	**58**

Source: Association of Village Health Committee, Annual Report for 2017.

During the CAH programme implementation, the Republican Centre for Health Promotion, with support from the CAH project (funded by the Swiss Agency for Development and Cooperation and implemented by the Swiss Red Cross), also developed a model for a CAH programme in urban areas, which has been introduced to all rayon centres and towns in the period 2014–2015.

Lessons learnt

The CAH programme in Kyrgyzstan demonstrates that a partnership between community-based organizations and the government health system is possible, is beneficial to both sides (the demand and provider side of the health system) and can be scaled up to a national level. It also shows that community empowerment processes and centrally designed health campaigns with measurable health outcomes can be combined and can mutually strengthen each other. Through this partnership, VHCs raised awareness of local communities about health that lead to the general public changing their views and behaviour. Given this development, a number of lessons can be identified and are outlined below.

Enabling circumstances for the development and expansion of the CAH programme in Kyrgyzstan can be attributed to a number of factors.

First is a supportive Ministry of Health. All ministers and key staff of the Ministry of Health recognized the need for health promotion and the importance of investing in it at the local rural level. They actively supported the idea of involving communities in health promotion. This was done by taking a more modern and innovative approach from the traditional so-called health propaganda or sanitary-hygienic education of Soviet times. When the pilot projects proved successful, the Ministry of Health included the programme's expansion in the health reform plan and established the necessary health promotion units in all oblasts. The support and financing by the Ministry attracted the support of additional donor agencies. All of this has contributed to the sustainability of the CAH programme in Kyrgyzstan.

The progressive health reform strategy, supported by the government, the Ministry of Health and donor agencies, with an emphasis on strengthening primary health care, created an environment highly supportive of health promotion and new ideas. Within health reform, the establishment of the Republican Centre for Health Promotion as a separate entity from the Department of Sanitary-Epidemiological Surveillance was helpful by creating the space needed for a new understanding of health promotion to take hold and for strong ownership to develop.

The early policy of decentralization embarked on by the Kyrgyz Government and the general desire of the Kyrgyz people to build a democracy encouraged attempts to build and strengthen civil society. The CAH programme's approach of setting up independent groups in each village was a good fit for this framework.

A very flexible main donor agency, the Swiss Agency for Development and Cooperation, allowed for experimentation and allocation of resources according to the priorities set by people living in the villages.

In addition a number of key elements of the CAH programme design may have led to its success.

The participatory bottom-up approach played a key role. Starting with people's priorities (instead of establishing people's priorities on the basis of a sample survey) a broad participatory reflection and action exercise was conducted, involving a large part of the population (several thousand meetings per oblast). This left people with the feeling that they were listened to (often expressed with astonishment and gratitude after the meetings). It also, as importantly, changed the perceptions of local health care staff, who realized that often lay people are capable of correctly analysing the relative importance of different diseases and their determinants. For the first time, health care staff learned to see people not as passive objects who need to be taught what is good for them, but as active subjects who are a resource and partner in the fight to improve health. This process is indeed crucial for creating the conditions for community trust and resilience building.

Designing health actions according to the priorities identified by people gave the programme credibility and increased volunteers' readiness to become involved, as they felt the programme took their opinions seriously. Most priorities identified by ordinary people did not conflict with the main priorities of the public health system. Early results of these health actions won support from donors and the health system for longer-term investments.

The CAH programme also put great emphasis on organizational capacity building to help VHCs become independent civil–society organizations. This convinced VHCs that the programme wanted them to be capable of pursuing their own agendas, which increased their interest and sustainability. It also boosted their motivation to carry out health actions. Implementing the health actions and receiving positive feedback and recognition, enhanced the organizational strength of VHCs. Thus, the two components mutually enhanced each other, creating supportive environments that enable community resilience. Despite the programme closure in March 2017, the Ministry of Health continues to finance health actions implemented by VHCs.

Encouraging VHCs to seek support from and collaborate with local self-government bodies meant that they had another local partner besides the local health care providers and health promotion units. This relationship, and the link between the rayon health committees and the rayon administrations, will be increasingly important for addressing determinants of health.

Finally, the CAH programme's heavy emphasis on non-dominant behaviour by professional staff vis-à-vis VHCs has been crucial to fostering a relationship of equal partners with VHCs. This equal partners relationship gives VHC members the respect, confidence and recognition needed to take on new tasks, grow into new roles and develop leadership capacities. This is one of the many reasons why these volunteers are motivated to offer their time and effort for the benefit of the community. Most VHC members are women (about 90%) (4). There are countless stories about female members who used their involvement with VHCs to become engaged in the community. The experience of working with VHCs taught them to shed their hesitation of public appearance and to speak up in public. Many have become respected leaders in their villages. The process and outcomes related to VHCs has strengthened community resilience and health literacy in the Kyrgyz local rural population.

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Spain. Strengthening resilience in the Roma community

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Abstract

The evidence is clear that members of the Roma community in Spain have worse health outcomes than the rest of the population. This inspirational example outlines some of the main reasons this occurs. More importantly, it shows that addressing issues related to prejudice and stigma and building mutual trust between national and local institutions and the Roma Spanish population are possible. The processes used to strengthen resilience within the Roma population are described, as well as the main lessons learned.

Issue

The presence of the Roma Community[11] in Spain was first documented in the 15th century. Between 1499 and 1783, over 250 specific legal texts were enacted aimed to assimilate, eject or even physically eliminate the Roma people (1). Article 14 of the Spanish Constitution enshrines the principle of non-discrimination on the grounds of birth, race, sex, religion, opinion or any other personal or social condition or circumstance. However, surveys continue to confirm the persistence of a deep-rooted social prejudice against the Roma community. A recent survey showed that over one third of respondents would feel unease having Roma people as neighbours (2). The manifestation of prejudice in discriminatory attitudes and practices hinders the full development and social inclusion of the Roma community in Spain and places them at the forefront of the most rejected groups within the country.

This story of persecution and discrimination has influenced the way in which the Roma communities have been resisting, responding and coping over the years. Among other things, this process has developed mutual distrust between Roma and non-Roma people. It has also produced a wide distrust among Roma people towards societal institutions and services, including the health sector (1). It is crucial to keep in mind this background of discrimination, which leads to poorer working and living conditions, in order to better understand the health outcomes of the Roma community.

Resilience is a core aspect in the construction of the identity of the Roma community. Its history of persecution could also be read as a narrative on resilience, adaptive capacity and successes. It is common for Roma people worldwide to combine and share different occupations, which require manifold skills. The extended family networks of the Roma community, as well as their remarkable ability to adapt to different geographical contexts, enable them to better seize local opportunities. These strategies and coping skills can be regarded as cultural strategies of resistance against discrimination and lack of opportunities. The lack of centralized Roma structures and the strongly cohesive familial relationships can also be regarded as a resistance strategy (1).

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[11] Roma is the term commonly used in European Union policy documents and discussions, although it encompasses diverse groups such as Gypsies, Travellers, Manouches, Ashkali, Sinti and Boyash.

The normalization of the relationship between Roma people and Spanish health services is relatively recent, dating from the end of the 1980s. Until then, an important part of the Roma population did not have health care coverage. Even today some Roma families still find it difficult to navigate a health system that is not adapted to certain cultural characteristics and needs of their members.

The first National Roma Community Health Survey, launched in 2006, represented a milestone as it was the first health-related representative study of this population. The Survey was designed after the methodological guidelines of the Spanish National Health Survey, which facilitated comparisons with the general population. The goals of the National Roma Community Health Survey were to assess the health status, and to shed light on issues related to lifestyles and access to health services by the Roma community. It took into account the social determinants of health and assessed the magnitude of inequities affecting the Roma population in comparison to the general population.

The Survey concluded that such inequities existed and were very relevant. It showed a clear social gradient of health with inequalities for the Roma people who had worse health outcomes in most health indicators as compared to social groups that traditionally fared better and worse than them. Differences in health indicators persisted when disaggregating data by socioeconomic indicators, educational level or housing type (3). An informative summary of the Survey is available in English (4).

The second National Roma Community Health Survey, launched in 2014, confirmed the persistence of inequities compared with the general population, although some minor improvements were also evident. However, only 65.3% of Roma men and 55.5% of Roma women considered their health status to be good or very good. The difference with men and women of the general population reached 12 and 15 points respectively. Roma men reported suffering more from arthritis, chronic obstructive pulmonary disease, diabetes, depression, mental health problems and migraines compared to other Spanish social groups. Roma women reported higher rates of hypertension, arthritis, asthma, diabetes, cholesterol, depression, mental health problems and menopause-related problems. Inequities with regard to general population increased with age. The second Survey also showed that Roma men and women suffered more accidents than the general population. Roma men reported higher rates of heavy daily smoking (5).

Compared with the data of the first Survey, inequities with regard to the general population had actually increased for indicators such as health status perception. Diabetes prevalence among Roma women grew almost six points, up to 14.5%. Inequities in tobacco consumption had also grown, with Roma women initiating cigarette smoking earlier than in the general population group. Overweight and obesity disparities were maintained within the eight-year period between the two surveys, but the rate among Roma boys had practically doubled. Non-intentional injuries among Roma women had also worsened since 2006. The improvement in some health indicators among the general population indicates that inequities increased between 2006 and 2014 (5).

In conclusion, despite the universal character of the Spanish national health system,[12] some population groups still face important barriers, particularly the Roma community. To avoid barriers, the Spanish health system is making efforts to offer equitable, accessible, high-quality health services for all populations, and is sensitive to vulnerable groups as acknowledged by the national legislative framework. Within this process, it is therefore crucial that national

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[12] Spain recognizes the right to health of all people through it Constitution and other acts such as the General Health Act 14/1986, Act 16/2003 on Cohesion and Quality of the National Health System and the Public Health Act of 2011.

health system strategies and practices are particularly attentive to the needs of the Roma people. In accordance to the National Strategy for the Inclusion of Roma People, the different administration levels that structure the Spanish system should continue monitoring these inequities and take action to reduce them (6).

Action

The State Council for Roma Community, a consultative national inter-ministerial body, offers the framework for collaboration between the Roma associative movement and the national-level administration (Ministry of Health, Social Services and Equality) (7). Council activity is organized through different working groups: social action, equal treatment, non-discrimination and European agenda, education, employment, health, housing and culture. Recommendations emerging from the surveys mentioned above, as well as the prioritizing of intervention areas, are agreed upon with the Health Group of the State Council for Roma Community.

In this framework, a small number of Roma associations have been developing health programmes. These have led to a process that is fostering effective collaboration between Roma associations and health administrations. This promising development aims to achieve better and sustainable health outcomes for the Roma community, and to contribute to health equity and health empowerment. The direct participation of Roma associations is a key element to this process and for health promotion to improve environmental, social and economic conditions.

The Equi-Sastipen-Rroma Network[13] was created in 2010 with the goal of increasing the number of Roma organizations interested in developing health-related interventions, since most organizations were mainly focused on domains such as education, housing and employment. The Network started with only six member organizations, and it currently brings together 21 Roma (nongovernmental) organizations from all over Spain. It aims to develop health promotion community interventions aligned with the priorities established by the National Strategy for the Social Inclusion of the Roma Population 2012–2020 and to advance implementation of the priorities established by the Health Group of the State Council for Roma Community.

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Outreach work for a smoke-free environment campaign in Spain.

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[13] The WHO Health Promotion Glossary defines network as a "grouping of individuals, organizations and agencies organized on a non hierarchical basis around common issues or concerns, which are pursued proactively and systematically, based on commitment and trust" (8).

A main goal of the Network is to promote and enhance the health interventions conducted in cooperation with the Roma community and health administrations. Furthermore, it aims to empower the Roma population to respond to discrimination and to ensure its participation to transform health-damaging environments. The Network maintains that health promotion offers a comprehensive and adequate framework to address the challenges and opportunities for health of the Roma population.

Network members are offered training in health promotion within the health equity and social determinants of health approach. Mediation skills and improvement of intercultural competencies of health professionals and peer education, and the improvement in the effective use of health services are guiding principles and main topics of training.

Members of the Network define Equi-Sastipen as a family, moving forward thanks to the love and respect of each member. This family symbolism is very important as Roma family relationships have always been a key factor in resilience and resistance strategies against social discrimination and rejection. Many members acknowledge and appreciate how the Network prioritizes the relational aspects of membership, calling it *muy gitana* (very Romany). They prefer this to their previous experiences in other networks which prioritized technical operations over family relationships.


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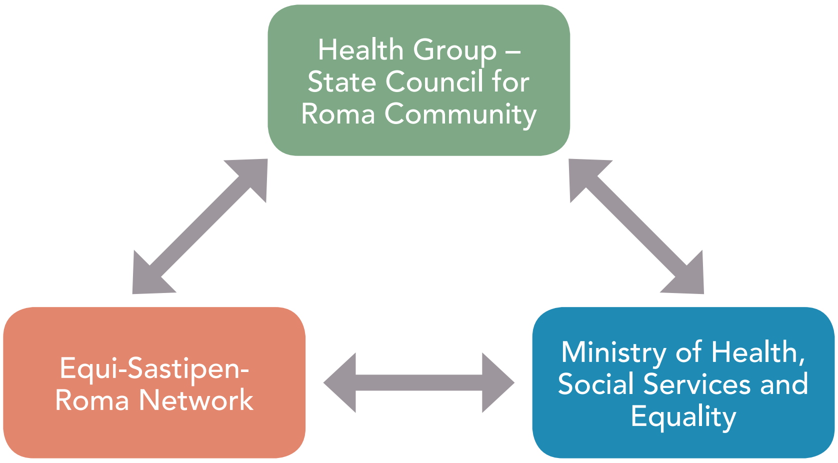
The Network is composed of representatives of Roma associations throughout Spain. It is explicitly committed to developing health promotion interventions in each province and enhancing social participation and social inclusion while preserving the Roma identity.

The Network is a useful tool to facilitate access to health services and to promote health equity for Roma people. The General Directorate of Public Health, Quality and Innovation of the health ministry participates as a Network member and monitors its actions while collaborating via technical support and consultancy (Fig. 2.5).

The Network meets at least twice a year for training seminars, usually in Madrid, at the Ministry of Health, Social Services and Equality facilities. Different online tools have been developed to facilitate exchange of experiences and documents in between seminars. The Network aims to build shared methodological guidelines, best practices and tools for intervention, training and evaluation. This work is reflected in the handbook published by the Ministry of Health, Social Services and Equality (1).

Fig. 2.5. Collaborative Roma entities



Other relevant activities include regular training seminars for intercultural health mediators for Roma organizations in different regions such as Andalusia, Aragon, Asturias, Cantabria, Castile-Leon, Catalonia or Valencia. In collaboration with the Public University of Navarra, an online training course was also developed. In recent years, training activities on intercultural competence for health professionals have been conducted in two different fields. Undergraduate training programmes have been established in medicine, nursing, social work, social education, etc. in collaboration with different universities. In collaboration with local and regional health authorities, regular training has been targeted to health care and social service professionals to improve practice and raise awareness on Roma issues.

This emphasis on intercultural competence is pertinent to resilience and empowerment. It is key to network success as it focuses not only on changes to be made by the Roma community but also on the steps needed for social, institutional and professional transformations required for a constructive intercultural encounter and the creation of supportive environments for health and social development (1,9).

Impact

Prior to the creation of the Network, only two Roma nongovernmental organizations in Spain were implementing health interventions. Currently, 21 are developing health promotion programmes, spreading their work to nine Spanish regions. This is a remarkable achievement of the Network.

Between 2010 and 2017, over 65 training activities were conducted in 13 of 17 Spanish autonomous regions. About 2500 social and health professionals benefitted from these training activities. Nowadays, there is more awareness of health issues facing the Roma population and more literature on how to better address these issues by cooperative efforts and trust-building activities between the Roma communities and health administrations and services.

The Network enhances not only community resilience by promoting solidarity, mutual care and trust between its members and their organizations, but also individual resilience. While participation in the Network is open to non-Roma staff members of organizations, individual resilience enhancement is particularly evident for Roma participants. All participants in the Network, regardless of ethnicity, benefit from training and learn to trust their skills and the impact of their work.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An Equi-Sastipen-Rroma Network workshop takes place in Spain.

During a focus group with Network members held in December 2017, several participants stated that at the personal level, being part of the Network provided them with a different way to think about and look after their own health. Participants frequently referred to health determinants and their impact on health as a result of the awareness and training they had received. A young Roma woman highlighted how important it was for her, but also for her organization and the Network as a whole, to count on institutional support. The support and acknowledgement provided by the Network and the Ministry transcended the professional aspect and transformed the personal and community rejection she felt by society into a healing experience.

Support from the Ministry of Health, Social Services and Equality to the Network combined with their shared vision of health, equity, participation and intersectoral focus were also used as a means to engage with different regional health authorities. This is a crucial component of the Network, as health services and intervention competences are mainly under the jurisdiction of the 17 autonomous regions in the Spanish system.

Other assets identified by Network members include the leadership of the coordinator and the vision for the composition and functioning of the Network. Respect is given to elders in the Roma culture; therefore, a senior person serves as the coordinator. Prioritizing technical staff from Roma associations over those with more political profiles implies that the internal dynamics within these organizations have also changed, resulting in increased trust and functional delegation to those who might not otherwise have these positions. Members also agreed that as Roma and non-Roma people live together in society, having the Network composed of both population groups is important, as long as their shared goal is working for better health outcomes for the Roma community.

The Network can only accommodate 50 members, as this is the number of provinces in Spain. Network success is attributed to the fact that functioning and relational aspects are easier to develop in a group of around 25 people. Limiting membership to one participant from each province and the gradual inclusion of provinces provides the Network with flexibility and functionality. The clear goal is to help develop equity and high-quality health interventions for the Roma population in the participant territories, and to support the work done by members, rather than managing projects or becoming too large to be effective.

Participation in the Network provides individual benefits to its members (training, capacity building, professional and personal support, etc.). Members share these benefits within their organizations, which, in turn, pass them on to the local community they serve. In doing so, the

Network facilitates the meeting point between the perceived needs of the Roma community and the institutional framework of policies and strategies, both national and international, as the starting point for interventions.

Mr José Antonio (Román) Jiménez, Coordinator of the Equi-Sastipen-Rroma Network and President of Asociación Gitana UNGA (far left), performs intercultural mediation in Spain.

Finally, another key positive element stressed during the focus group was the predominance among the membership of young people ("which means that we, seniors, did well and generated an interest") and women ("which makes ours not only a Romany Network but also a feminine and sincere Network").

The analysis conducted in the focus groups identified types of resilience capacity that are reinforced by the Network. Resilience-capacity literature identifies four types.

Adaptive capacity strengthens the abilities of network members, as well as their organizations to better understand, mediate and negotiate with mainstream society as a result of awareness raising and training to reduce health professionals' prejudices.

Absorptive capacity strengthens the abilities of Network members, providing tools that help them recover from adverse conditions, using available skills, resources and assets.

Anticipatory capacity is the participation and action of intercultural health mediators that is instrumental to predict and reduce the risks related to discrimination and prejudice within health services and that helps to minimize the vulnerability of the Roma community.

Transformative capacity is the training and awareness raising activities conducted by the Network in transforming health services, making them more sensitive to the needs of the Roma. Examples include adapting waiting rooms in health services to make them more welcoming to families of Roma patients, and practices such as addressing the eldest member of the family as next of kin, that is, putting into practice and implementing the recommendations of the Handbook for Action in the Area of Health Services with the Roma Community (10). The participation of the Ministry and Roma associations in the Network provides first-hand information of the needs of the Roma, which is essential for more responsive and inclusive policies.

Lessons learnt

The Network has evolved towards generating resilience at different levels. Network success is partly owed to the composition and nurturing of active and highly motivated members. They are willing to transform and improve their lives, and are committed to generate positive changes, moving towards a common goal and sharing generously their experiences and knowledge, with the motto "strength in numbers".

The flexibility of the Network is key to its success. The gradual inclusion of new members and the integration of Roma community cultural values provide for professional and personal development. Integration of non-Roma technical staff, the particular way of building relationships and communications between members, and the fact that conflicts are addressed within the Roma culture (with intervention and mediation of elder members of the community) are three key elements for its functioning as a "Romany Network".

Besides the stronger leadership of the Network coordinator, there exists a technical team with great attention to detail and the ability to effectively coordinate and follow up on Network decisions and activities. The sustainability and success of the Network is achieved through a balance between technical, human and generational support.

The fact that Network members have followed a common training and development pathway has helped in developing vision, priority of action and a shared language.

Participation of the Ministry of Health, Social Services and Equality as a Network member provides it with adequate institutional acknowledgement and the guidance obtained facilitates the adaption of policies. The Network is also working on online training for national health system professionals in collaboration with the Ministry to achieve a multiplying effect in disseminating knowledge about the health needs of the Roma community.

However, some barriers and challenges should also be mentioned. Financial sustainability remains an issue, since Network activities are dependent on public funding. New scenarios, such as funding for the community-led health promotion interventions developed by individual organizations have recently been transferred from the national to the regional level in 2017, implying the need for awareness raising in new stakeholders who may not be sensitive to the health needs of the Roma. Thus, more work needs to be done to address this challenge.

Plans for the future include expanding networking and collaboration from Spanish autonomous regions to the local level through, for example, the Spanish Network of Healthy Cities.

Acknowledgments

The authors would like to thank Mr José Antonio (Román) Jiménez and Ms Marlen Menéndez, coordinators of Red Equi-Sastipen-Rroma and Mr Javier Arza, Technical Assistant, for their contributions and support in describing this example. Thanks also go to all organizations participating in the Network and their individual members for their generous input:

- Asociación Barró
- Asociación de Mujeres Gitanas Alboreá
- Asociación de Mujeres Gitanas Sinando Kali
- Asociación de Mujeres Gitanas Universitarias Amuradi (FAKALI)

- Asociación de Promoción Gitana de La Rioja
- Asociación Diversia Romí
- Asociación FAC CALI
- Asociación Gitanos de Hoy
- Asociación Romí Sersení
- Asociación SIM ROMI Gipuzkoa de Mujeres Gitanas
- Coordinación Asociación Gitana UNGA de Asturias
- Federación Andaluza de Mujeres Gitanas
- Federación Autonómica de Asociaciones Gitanas de la Comunidad Valenciana (FAGA)
- Federación de Asociaciones Gitanas de Aragón (FAGIC)
- Federación de Asociaciones Gitanas de Cataluña
- Federación de Asociaciones Gitanas de Navarra (FAGA)
- Federación de Asociaciones Gitanas Extremeñas (FAGEX)
- Federación Española del Pueblo Gitano
- Federación Nacional de Asociaciones de Mujeres Gitanas Kamira
- Federación Regional Gitana de Asociaciones de Castilla La Mancha
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United Kingdom (England). Strengthening resilience in neighbourhoods by promoting social connections and community networks for older people through Age Better in Sheffield

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Abstract

Loneliness and social isolation poses a major social and public health challenge in the United Kingdom, as well as in other European countries. This inspirational example shows the type of activities undertaken by Age Better in Sheffield (ABiS) to strengthen resilience by tackling loneliness and social isolation and promoting social connections in the older population. The example shows innovative practices in terms of intersectional working and in efforts to co-production of health and well-being by a multitude of institutional and local lay resources. These innovative practices result in co-designing of services and supportive environments that strengthen resilience and reduce loneliness and social isolation of which older populations are often at high risk.

Issue

An established evidence base explores the complexity of loneliness and social isolation, its prevalence in key social groups and its impact on physical and mental health and well-being (1). Research findings (2) indicate that

> *the influence of social relationships on the risk of death are comparable with well-established risk factors for mortality such as smoking and alcohol consumption and exceed the influence of other risk factors such as physical inactivity and obesity.*

Research on loneliness in the United Kingdom has mainly focused on older people. Research indicates that 6–13% of the United Kingdom population describes being often or always lonely. The research on prevalence by Age UK indicates that 7% of people aged 65 and over state they always or often feel lonely (3). Adding in survey respondents who report that they "sometimes" feel lonely raises the figure to 33%. For the 80 and above age group, figures show the steep rise in reported loneliness, characterized by a lack of companionship.

The terms loneliness and social isolation are synonymous; however, differentiating between the concepts is beneficial. Social isolation is described as an individual's separation from social and familial contact, community involvement or access to services. Loneliness is understood as a personal and subjective feeling of dissatisfaction and a sense of lacking the resources to the extent that they are wanted or needed (3). Elsewhere, loneliness is typically defined as the difference between a person's desired and actual social relationships (4). It is conceptually distinct from social isolation, which describes the quantity (rather than quality) of an individual's social contacts. The English Longitudinal Study of Ageing (ELSA) (5) provides a four-stage concept of loneliness as:

- feeling a lack of companionship
- feeling left out
- feeling isolated from others
- feeling in tune with other people.

A commonly held view is that an individual can be isolated without being lonely and conversely, lonely without being isolated.

Action

The ABiS programme focuses on strengthening community resilience and taking action to promote social connections and participation to ameliorate social isolation and loneliness in older people. Action within the ABiS programme seeks to build local capacity and the social capital of communities, two features which are integral to community resilience (6,7).

It seeks to achieve four main outcomes.

- Older people are less isolated.
- Older people are actively involved in their communities with their views and participation valued more highly.
- Older people are more engaged in the design and delivery of services that help to reduce their isolation.
- Determine if ABiS programme services are more successful if they are better planned and coordinated by those who are meant to use them.

The evidence base on loneliness and social isolation sets out the types of interventions that are useful in improving potential social and interpersonal experiences (8). The ABiS programme used this evidence to understand and develop the types of services and resources older people may require maintaining social networks and connectivity. Promoting resilience while tackling loneliness and social isolation requires developing new resources and a strong commitment to the principles of co-production and co-design in social care. These principles focus on involving local individuals and organizations as equal partners and contributors in the process of developing and delivering community and public sector services (9,10).

The ABiS programme acknowledges that wider social determinants also play a significant part in people's resilience and their experience of loneliness. The interventions delivered through the ABiS programme seek to address these factors. The experience of social exclusion is an important variable in loneliness. Evidence from ELSA surveys (2002 and 2008) categorizes social exclusion by seven domains:

1. social relationships
2. cultural
3. civic activities and access to information
4. local amenities
5. decent housing and public transport

6. common consumer goods
7. financial products.

Experiencing exclusion in three or more of these areas was associated with almost a threefold increase in the risk of becoming lonely. The ABiS programme is based on this evidence.

The scope of the population challenge in the ABiS programme is comparable to that of many other large urban areas in England. A housing association developed this initiative and then reframed and oriented its focus towards a health assets model. The first key feature of this model is skilling the workforce in conceptual frameworks for understanding what creates health (a salutogenic approach) and in relational skills to foster and enact activity that promotes local citizen engagement, and seeks to co-create initiatives that build resilience and community action.

The second key feature is the focus on developing and delivering services through local partner agencies, building and utilizing the strengths and assets within that sector. A third and critical feature is the commitment to involve community members in all stages of development and delivery. These stages are congruent with the theory of change model proposed for asset-based approaches for health and well-being (11,12). This model sets out critical steps for organizing action to promote health and well-being and to strengthen resilience. The states of the model can be seen in terms of actions and partnerships across organizations and agencies, and in terms of actions within communities. When actions within these stages are activated, opportunities for building community resilience can become systemic.

Sheffield is a post-industrial city located in the county of South Yorkshire in the north of England. Population in 2016 was 575 400 in 229 928 households. The city is England's third largest district authority. Single occupants comprise almost a third of all households. Sheffield's population is projected to increase by around 88 600 people over a 25-year period to 652 300 in 2039. Projections indicate that from 2023 on, the population will shift to include more males than females due to increased male life expectancy coupled with higher male in-migration. Figures also suggest that the number of people aged over 65 will grow by 42% in the next 25 years, while the number of those aged 85 and over will more than double. Sheffield is historically an ethnically diverse city, with around 19% of its population from black or minority ethnic groups. The largest of these groups is the Pakistani community making up 4% of the population, but Sheffield also has large Caribbean, Indian, Bangladeshi, Somali, Yemeni and Chinese communities. Recently, the city has also seen a growth in its Roma communities (13).

In response to the growing age profile, the ABiS programme offers a positive approach to health promotion and to building community resilience through personal and collective action on reducing risk factors and facilitating processes to promote human resource development (14). It mobilizes local neighbourhood resources while ensuring that sector agencies are engaged in community-focused approaches and collaborate to deliver appropriate responses to key population groups.

It seeks to avert the conditions that contribute to social isolation and loneliness. It mobilizes a range of actors and agencies to raise insight in the types of actions necessary to promote social connections, help transform local systems, develop a cross-agency ethos, and empower local communities to shift resources to areas of concern.

South Yorkshire Housing Association (SYHA) is an established social housing programme across the Sheffield city region[15] in the north of England that provides 6000 homes. In the Sheffield area where the ABiS community resilience programme focused, SYHA has 2031 tenants aged 50 years and older, with 689 people receiving additional health and well-being support alongside their tenancy.

In 2014, SYHA led a bid for funding from the Big Lottery Fund,16 which led to a £6 million investment over a period of six years to develop and implement the ABiS programme. The Ageing Better initiative is a six-year, England-wide £78 million National Lottery funded programme set up by the Big Lottery Fund, working across 14 partnerships. It aims to support older people by creating new and enjoyable ways for them to be actively involved in their communities, helping to combat social isolation and loneliness.

Through this funding, SYHA aimed to develop a campaign, a range of community-based resources and neighbourhood-based activities that promote social connections and networks. The overall initiative is a collaborative venture with a range of locally-based delivery agencies and community groups that promote mental health and well-being across the city.

The overall initiative is governed by the ABiS Core Partnership, which includes residents from local neighbourhoods representing older people and representatives from Sheffield City Council, NHS Sheffield Clinical Commissioning Group, Sheffield Hallam University, the voluntary, community and faith sectors, and SYHA. These sector organizations are involved in broader health and well-being initiatives within the city. Each partner within the collaborative provides specific expertise and interventions that forms part of a whole endeavour.

In developing the overall strategy and approach, ABiS conducted a citywide survey of 509 older people that provided insight into the causes and solutions to loneliness. It facilitated 12 creative co-production events and developed certain ambitions to realize the initiative that included:

- building capacity within 120 organizations to impact on social connections and networks and reduce loneliness and isolation;
- engaging 800 people aged over 50 years to participate in key areas of ABiS including roles as peer/intergenerational volunteers;
- transforming choice by commissioning creative and innovative projects; and
- developing and supporting projects that reflect an evidence-based framework for action on well-being.[16]

In order to describe the type and rationale of activities undertaken within or in collaboration with the ABiS programme, the following questions should be addressed.

- How does ABiS work for local people?
- What resources are available to people?

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[15] The Sheffield city region includes neighbouring conurbations in the local authorities of Rotherham, Barnsley and Bassetlaw.

[16] Since 2006, the Big Lottery Fund has invested £2.5 billion in over 56 000 projects: from community centres and parks to homeless shelters and counselling services. These projects have improved lives, transformed communities and created thousands of jobs and volunteering opportunities. BIG is an executive non-departmental public body, sponsored by the Department for Digital, Culture, Media & Sport of the Government of the United Kingdom.

How ABiS works for local people

Regarding the first question, the interventions and methods of working designed into the programme seek to enhance social support and to increase the range and opportunities for social interaction within key locations and age groups. A key premise is to focus on assets[17] and strengths that exist within individuals and local communities that could either be reactivated and/or realized. The city has a wealth of assets that if mobilized could augment the overall initiative; therefore, a number of early structural actions were designed.

First, a core ambition was to develop a cadre of neighbourhood-based volunteers who would participate in and lead key projects across the city in neighbourhoods identified as having marked levels of social isolation and loneliness – or where the demographic indicators for this were present.

SYHA with all partners set a target to recruit 3000 volunteers into the programme by 2021 to become a sustaining force in taking forward the ethos and practices; this seeks to build in future sustainability with local community members and is a way to promote ownership and further action. Volunteers offer a range of skills and resources, and so-called micro-volunteer options allow people with limited time to participate in specific but highly relevant projects in the overall endeavour. Examples include volunteer roles to support and enable the initiative to flourish, such as technical skills in graphic design, web media etc. to enhance the projects' profile.

A second crucial element within ABiS was to raise awareness within the sector workforce that would have contact with (older) people in key neighbourhoods and communities. An information package was developed describing the issues of loneliness and social isolation, and a core framework through which frontline workers could understand, react and support people to access local resources. The aim was to engage 1000 core staff members and then to cascade the awareness down into peers with an ambition of reaching 10 000 staff by 2021.

These structural elements are crucial to the longevity of ABiS, seeding ownership and action within peer organizations and local neighbourhoods and communities. This contributes to a wider ambition in developing a healthy settings ethos across the city while promoting action toward health assets.


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Collective and individual action builds resilience and social connections.

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[17] The five ways to wellbeing framework is an evidence-based conceptual framework for creating a focus and action on well-being for individuals and communities. This tool has been widely adopted in the United Kingdom in recent years and was commissioned as part of the Government's work (15,16).

ABiS is committed to build resilience by fostering personal and collective resources for health and well-being and for tackling health inequities. Thus, ABiS delivers a range of resources and opportunities for social connections and civic participation at a neighbourhood level. This is achieved through its collaborative partnership arrangement with local agencies engaged in community development and a commitment to co-creating innovative options with local people and community/neighbourhood groups.[18] Local sector agencies are commissioned to develop and deliver these resources. Building on the strengths in place, each agency will seek to promote social value through providing grant funding to enable new projects to be developed.[19] ABiS see this as a positive legacy and approach to stimulating action more generally across the city.

Available resources

As for the second question, ABiS has developed a number of resources (19), with the most relevant listed below. Quotations from people involved in the programme show the diversity of resources.

SYHA has adopted principles of co-design across all its well-being programmes, enabling local people to engage with creative and flexible approaches to design the focus, content and methods for action seeking to improve well-being and resilience. In the ABiS initiative, staff facilitating the co-design approach provided opportunities in local neighbourhoods for people to come together to design a resource and information toolkit. These events were transgenerational, and people use a range of mediums to present stories about individuals that live in the neighbourhood, telling stories of what it is like to grow older in the area. This material provides tips, advice and guidance on the steps everyone can take to promote social connections and reduce isolation and loneliness. Examples of an **age better toolkit** and supporting information are online (20).


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Providing local support to older people enables social access and connection.

Age Better Champions help people over 50 with isolation and loneliness using the New Economics Foundation's five ways to wellbeing framework (15). They are volunteers, often with lived experience of loneliness and social isolation, who can work in groups or in one-to-one sessions to explore simple everyday activities designed to boost well-being and reduce isolation. Voluntary Action Sheffield is an organization that provides Age Better Champions.

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[18] Community means two things: communities of interest and similarity. A neighbourhood is a specific geographical space/location.

[19] Definitions and detail on social value in the United Kingdom are available online (17,18).

> *Getting older means your body is wearing out and you need to take more care of it. To keep healthy the wellbeing of the mind is as important as the body. I want to help others to enjoy a long and healthy life.*

Linda, Age Better Champion

As part of the diagnostic exercise that informed ABiS, many older people spoke of the challenges posed by transport and access and how this creates experiences of isolation and loneliness. SYHA leads a volunteer-based intervention – **Access Ambassadors** – that links together people aged 50 and over to work together where transport and access issues in communities are the main causes of isolation. This could be help from someone to leave the house, building confidence to use a mobility scooter or support with access to public transport. Access Ambassadors also help broker contact with statutory and sector agencies to raise awareness of travel and access issues, such as working with local highway and transport providers on potential solutions to improve transport links and access.

> *Although I've never felt isolated myself, I still wanted to be able to go for a walk in my street. The Access Ambassadors are helping me continue to 'be active' by accompanying me when I go out. I would encourage everyone to get involved – they will help you to do as much or as little as you please to help you gain confidence and get out more.*

Nora, aged 101 years

A local partnership agreement delivers **well-being practitioners** who provide intensive counselling to people over 50 years who experience low mental well-being, which affects their ability to engage and interact outside of their home. This service can be offered in a person's own home or at a venue where the individual feels comfortable. It offers one-to-one contact or a range of group therapy options. The aim is to build personal confidence and empowerment to make use of local resources. This is often a gateway to engage with the wider resources available in the programme. Sheffield Mind is an organization that provides these services.


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Reciprocal relationships build trust and well-being.

The guiding principles of ABiS are to promote well-being and resilience and seek to prevent the potential for social isolation. The Peer Mentor project is targeted at people aged 50 or over who are most at risk of isolation. **Peer mentors** are volunteers from local neighbourhoods and communities who support people with certain life transitions that may lead to social isolation and loneliness (for example, retirement from work, loss of a loved one, ill health). They support individuals by identifying personal and local resources that promote well-being. These resources and subsequent actions come from the five ways to wellbeing framework (15). SHYA provides a core training programme for mentors to equip them to effectively support people, and ensures that volunteers have clarity of role while seeking to ground their contributions in a clear frame for action. Voluntary Action Sheffield is an organization that provides peer mentoring.

> *I wanted to volunteer to help myself but also give something back to others. It's important when you're on your own to mix – it helps your well-being when you can socially interact. Courage is a big thing, to have someone go along with you that first time helps.*

Janice, Volunteer Peer Mentor

Intergenerational Skill Swap gives people over the age of 50 and people under the age of 50 the opportunity to swap a skill, drawing on one of the key tenets of asset-based community development, sharing skills with neighbours. The idea is that this will be mutually beneficial for each person and allow opportunity for socialization. Volunteers demonstrate or teach skills at community-based meetings. The skills are diverse and range from growing vegetables to using digital technology to making contact with others. Often those sharing skills are people who have personal experience of loneliness and social isolation and may have been a recipient of the ABiS programme. Volunteers are not always local community members but may come from other neighbourhoods. The intervention is offered on a one-to-one basis and also within groups. The Women's Royal Voluntary Service is an organization that offers this service.

> *I wanted to join the Intergenerational Skill Swap where skills can be given and taken. I personally would like someone to show me their skills in cooking. I used to have lots of experience in it but not anymore as cooking for one person is not as easy as cooking for a family. I hope this project help me to get my skills back.*

Edna Woodman, age 89, Intergenerational Skill Swap participant

Sustainable solutions form a core focus in the ABiS programme; **Start ups** is an approach to capacity and resource building in local neighbourhoods. Through ABiS, small cash grants (of up to £200) and support in media and marketing are made available to kick start neighbourhood-based action that promote social connection for people vulnerable to social isolation and loneliness. Action may be limited to a specific local neighbourhood or may involve projects and resources with a wider geographic reach. This approach is also congruent to established practice in asset-based and capability approaches to community development. To date, ABiS has supported circa 38 new neighbourhood initiatives ranging from dementia cafes to lunch clubs and exercise groups. Examples of culturally-specific initiatives are exercise groups for Asian women or for people of Pakistani origin. The organization Ignite Imaginations helps to design the proposed activity and get it up and running.

The **Innovation Fund Project** provides seed funding (up to £5500 for four months) to test proof of concepts for projects that promote social connection and use co-production approaches (21–23). As these projects are iterative once completed and tested further funding is available to sustain and scale up the initiative, this funding can be up to £36 000 for a year.

Innovation Fund projects are defined following a gap analysis to identify key groups and communities not represented in ABiS, and examples include seeking to develop projects for lesbian, gay, bi-sexual, transgender and queer communities, Chinese neighbourhoods and for men.

There are several examples of innovation fund projects in 2016/2017.

- Sheffield Mencap Carers' Circles supports anyone aged 50 and older who cares for someone with a learning disability, to extend their social networks and to improve their health and well-being.
- Age UK Khala's Place transforms a local space into a safe and inviting place where older Muslim women can meet, share experiences, learn new skills and contribute to the local community.
- The Alzheimer's Society 50–64 Project supports people (aged 50–64) who have dementia and their carers.
- Good Gym organizes group runs to help community organizations and vulnerable people. They also run to visit isolated older people, referred to as coaches because they motivate them.
- Living Streets brings together people of all generations to think about and enjoy the benefits that walking brings and ensure that all streets are fit for walking.

Innovation Fund projects are equally diverse for 2017/2018.

Heeley City Farm – Farming Comes To You engages with people aged 50 and over who want to be more connected to their community and involved in a new adventure. It hosts small animal-assisted therapy days around Sheffield at visiting care homes, community halls, sheltered accommodations, outside general practitioner surgeries and more.

Lai Yin Association – Smart Phone Smart Friends works with older Chinese people to use their smartphones for socializing and maintaining good well-being. Training courses, peer support and home visits primarily focus on developing skills in using WhatsApp, WeChat, Google and YouTube. Smartphones and apps help keep people connected with community members and local groups and events, as well as family and friends that live further away.

Aspiring Communities Together – Community Connectors deliver weekly sessions at the Fir Vale Centre and the Stubbin Community Centre. Sessions are based on improving and maintaining health and well-being, and suggestions for other topics are welcome. Community Connectors are local familiar faces who have extensive knowledge of what is going on in different communities.

Ignite Imaginations – We Are Makers showcases and celebrates the wealth of skills, experience and knowledge in the city, discovering unheard stories, demonstrating forgotten skills and developing new connections. Through a culmination of experiences, the project aims for local people aged 50 and over to be celebrated, inspired and more connected to their neighbours, community and local services. Ignite Imaginations hosts events to bring people together, celebrate the diversity of the community, and showcase and signpost what is already happening in the area.

Enrichment for the Elderly – Together supports the family and friends of people who live in a care setting. It explores how best to support visitors in having a more enjoyable visit to a care setting, and to improve confidence to share knowledge and skills with others. It encourages people to continue to be involved in the care of a family member/friend, and to create opportunities to share joy, meet others and gain a better understand of conditions such as dementia.

Impact

During the ABiS programme:

- 26 710 older people will be involved; reducing their social isolation and loneliness significantly; and
- 1750 volunteers will work with isolated and lonely people over the age of 50 to reduce the isolation levels of seniors.

ABiS is subject to an external evaluation which is conducted through the programme's funding body, the Big Lottery Fund (United Kingdom). This evaluation is part of a wider process of similar Age Better initiatives funded by the Big Lottery Fund across sites in the United Kingdom. This wider evaluation will report on what works at a national level to promote community resilience by improving social connection and reduce loneliness and social isolation. This full evaluation will be available in 2021 when all the national activity is completed.

SYHA has developed an evaluation approach to explore the impact from participation in the programme; this includes local people accessing the resources and those acting as volunteers on projects. Collaboration with a local university was established. As part of the mixed methodology, a cadre of peer researchers have been trained to gather qualitative data from participants. This is key to building skills and capacity in communities and reflects the overall ethos in the scheme towards empowerment. A range of validated measures will also be used to gather data on well-being and health status, including the (shortened) Warwick-Edinburgh Mental Wellbeing Scale[20] and EQ-5D-3L[21] (24).

SYHA also gathers sociodemographic data used to reflect on the reach and spread of the programme and to inform decisions on how to target and focus resources and action during the life of the project. For example, data show participation of men generally as low, so steps have been taken to develop interventions that respond to this.

Lessons learnt

Although the ABiS programme is still in development, a number of lessons can be already identified. The lessons learnt are not necessarily in a hierarchical order.

1. Engage local people – promote and secure involvement.

Experience in ABiS and wider programmes shows that people increasingly want to engage and co-produce activities that have meaning to their lives and want to feel heard and valued individually and collectively.

Prior to commencing the initiative, reflections took place on wider work in similar community initiatives, and the ABiS programme adopted some of these key learning principles, which shows congruence to its organizational values and behaviour.

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[20] The Warwick-Edinburgh Mental Wellbeing scale was developed to enable the monitoring of mental wellbeing in the general population and the evaluation of projects, programmes and policies which aim to improve mental wellbeing.

[21] The EQ-5D-3L descriptive system comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels: no problems, some problems and extreme problems. Patients indicate their health state by ticking the box next to the most appropriate statement in each of the five dimensions.

Encourage people to participate in planning and design activities. Create a flexible, creative and time-sensitive environment, so people can see the result of their co-production involvement and what has changed because of this. People have a lot to say in creating the right environment and will open up and share important stories and experiences which shape the focus and approaches within the initiative.

Offer a range of neighbourhood activities and events to suit different types of people and cultures to build and extend involvement and ownership.

Taking steps to provide peer support works well, and it is good for people to hear from others who have had similar experiences.

Monitor the sociodemographic factors to understand who is engaging and participating; with only 30% of men participating in the programme, new ways are needed to engage men and offer something that appeals to them (this uptake reflect a national trend in wider programmes).

Have a presence in communities, such as community connector/builder roles in the early stages of programme development. Use community development methods that reflect an asset-based approach (25).

2. Collaborate with partners.

Share new approaches such as design thinking principles and thinking environments with partners to build capacity and give them new tools to work with to ensure that creative, participatory approaches are core to joint working.

Having a core partnership made up of older people and professionals across sectors informs decision-making and strategic direction, and helps organizations and participants to think about praxis differently.

Engaging with agencies responsible for commissioning health and related programmes within a core partnership board helps to influence future decision-making regarding developing services and initiatives for older people.

This initiative, with its focus on collaborative and asset-based development and delivery offers an example to local public sector system leaders of health assets in action and serves to frame dialogue and an emphasis on what creates health in local systems.

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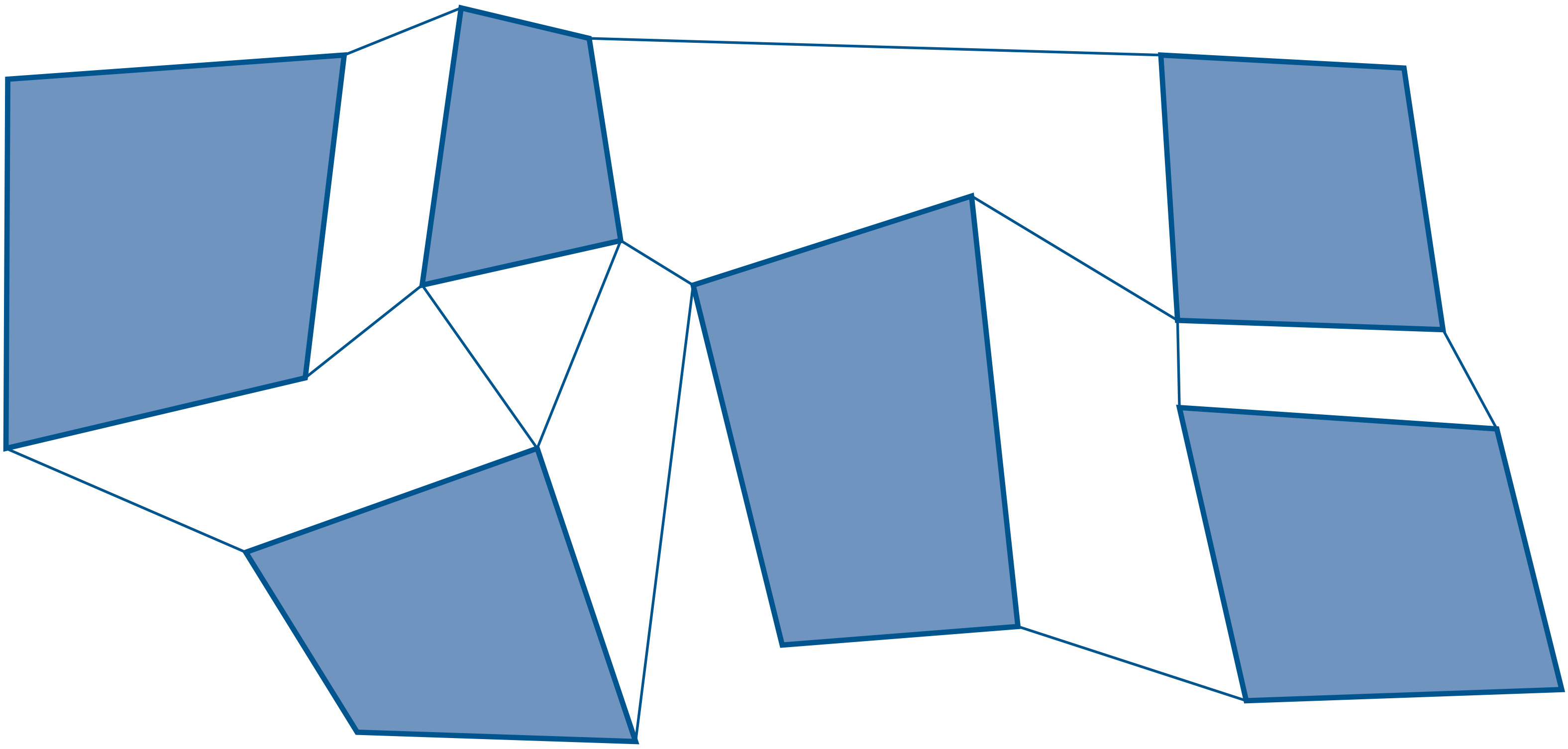
Part 3. Building resilience using community and bottom-up approaches

In many cases, action that contributes to resilience is the result of spontaneous community movements and bottom-up approaches. Such actions are not necessarily academically conceptualized and implemented following specific protocols or guidelines. They emerge from actions of social networks, self-help groups, community volunteer organizations or other forms in which civil society mobilizes itself. The narrative that describes the following inspirational examples gives a flavour of such bottom-up spontaneous action that builds resilience.

The inspirational examples in this category show that positive health outcomes can only be obtained by addressing factors that protect and create health and well-being. Most factors are related to community life, social connectedness and having a voice in local decision-making. Building community control and strengthening community resilience are crucial. The examples provide a wide range of innovative thinking and practices of bottom-up approaches to building resilience and control over community resources and decisions.



Bulgaria. Against all odds: local action in Varna to strengthen resilience and create supportive environments for people with disabilities

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Abstract

This narrative describes how Bulgarian disability nongovernmental organizations (NGOs) brought about social change to improve the lives of people with disabilities. The analysis focuses on two civil–society organizations in Varna. It highlights the elements that have built resilience to enable them to sustain themselves through the years. This inspirational example shows the process of building a bottom-up movement that aims to change society's attitudes towards disability and to develop supportive environments for strengthening resilience for people with disabilities. In Bulgaria, laws affecting people with a disability have changed over time. To better understand the impact of these changes, this narrative provides an analysis of the historical context covering the three main periods of recent Bulgarian history: socialism, post-socialist transition and the current era of European Union membership.

Issue

Historically, the rights of people with a disability developed differently between western and eastern Europe. The disability movement in western European countries already started in the late 1960s and early 1970s (1). Starting from the end of the Second World War, many eastern European countries were separated from western Europe, and they had limited rights and freedoms due to the regime in power. This different political and economic context in these two parts of Europe led to differences in the pace of development of civil–society activism. Countries of the so-called eastern bloc lagged behind in many issues of human rights, including the rights of those with disabilities. Many political, social, cultural and economic consequences affected eastern Europe following regime changes in the late 1980s. Regrettably, after the collapse of the Soviet Union in the early 1990s, the human rights of people with a disability were still disregarded (2). For decades, disability was not part of the public discussion in post-Soviet Europe.

Realizing that there was a lack of legal, political and social support for those with a disability, a small group of activists in eastern Europe provided the impetus for setting up networks and organizations that served the needs of disabled people and their families. Among those first examples of resilience strengthening in this domain are two NGOs in Varna, whose motto was *"Nothing about us without us"*. They set out to build pathways of inclusion and acceptance of people with a disability in Bulgaria. This bottom-up movement was designed to foster equality, empowerment and the promotion of independence and self-reliance (3).

Two disability NGOs were established in the early 1990s in Varna. The Karin Dom Foundation ("the home of Karin" in English) was established in 1992 for the purpose of promoting inclusiveness and acceptability of children in Varna aged 0–18 who had a disability. A Bulgarian émigré with philanthropic motives founded the organization and established a team of professionals (specialists from Bulgaria and abroad) to start developing programmes for children with special needs. The founder of the Karin Dom Foundation and his family provided the building and the initial physical facilities required.

Parents of children with mental disabilities established the second organization, the Daycare Center Riviera. They were motivated by the need to promote the rights of their children and those of other children in similar situations who often seemed invisible. Daycare Center Riviera was set up in 1994 using the personal funds of its founders. It focused primarily on people aged 18 or above who did not receive any services.

© Daycare Center Riviera

Carnival parade, Daycare Center Riviera, Varna, Bulgaria.

Action and impact

In order to understand the actions undertaken, the success achieved and the challenges faced, structured interviews with disability activists and families of children with a disability were conducted. These interviews help to explain the challenges in strengthening resilience through the current and past decades of political change in Bulgaria. Key informants involved in leadership and management of the disability-related organizations provided materials for the interviews conducted in December 2017. A thematic analysis of the data was compiled. This helped to filter the results into a cohesive narrative so that the *how* and *why* of the process of developing disability organizations could be comprehensively described. Quotations from individuals have been selected and translated into English to illustrate the range of viewpoints identified. The analysis of the interviews shed light on the action undertaken during three key time periods that characterize modern Bulgarian history.

Action during the socialist period

During the 45 years (1944–1989) of the socialist regime in Bulgaria, the treatment of people with disabilities was largely characterized by replicating the Soviet model of managing disability, in other words confinement, segregation and stigmatization (4). Disabled people (physically and especially mentally) were routinely placed in sheltered residential institutions. Disability was equated with inability to work, and patients were heavily medicalized (5). Organizations serving disabled people were subsumed by the state, affecting individuals and families in profound ways.

> *I had my first child in the 1970s. It was the "lottery" of life that my child was born disabled. I remember clearly how my disabled child and I had to hide behind the bushes in the park when we were out for a walk. I couldn't go for a walk with other people; I had to hide (she cries).*

Informant, Daycare Center Riviera

Her words provide evidence of the level of segregation and discrimination people with a disability faced. The failure of the institutions to care for disabled children took a profound emotional toll on families with a disabled child.

The lack of cultural awareness and insensitivity toward disabled people was also deeply crushing. The emotional pain that the parents of disabled children had to go through during this historical time was even deeper for women.

> *People always looked for an explanation as to why the child was disabled, and they blamed it on the mother."*

Informant, Daycare Center Riviera

A common practice under the socialist regime was to institutionalize children with a disability. Such institutions were often hidden in the suburbs of town or small and remote villages, away from the eyes of people. After the birth of a child with a disability, medical practitioners encouraged parents to put the child in the institution because: "There is no hope for your child. You'd better leave it and try to have another one." (Informant, Karin Dom Foundation).

Despite the pain and hopelessness, many parents did not leave their children in institutional care. People decided to act and do something for their children. Parents with similar problems formed groups. That was the beginning of the informal development of these pioneering NGOs. Both organizations started a process of resilience building, inspired by people who refused to take no for an answer.

In this context, resilience can be seen as an asset-based approach that helps individuals respond successfully to their disabling environments (6–8). Masten et al define resilience as "the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances" (9). For the initiators of the two Varna-based NGOs, the process of coping with negative life circumstances began with the family's decision to keep their disabled children at home, taking care of them and advocating for their rights.

Action during the post-socialist period

Disability NGOs in Varna significantly helped families and individuals with a disability to manage adversity in their lives. They had the role of a connecting mechanism in building resilience in individuals and communities. The process of resilience building was initiated when families decided to keep and take care of their disabled children at home, instead of putting them into segregated institutions. This is the crux of the resilience-building process shared among all members of the disability organizations that were interviewed.

The love of families toward their disabled children was essential. Mutual support and the sharing of responsibilities and difficulties in the family was the "personal injection of strength" needed to initiate the "organized battle for recognition", as described by the founders of the

Daycare Center Riviera.

> *During the first six years of my child's life I was the mother and the teacher at home. But after turning six, she had to start school… Schoolchildren with disabilities were forced to attend schools for children with special needs. In the class, there were 30 children with different disabilities and one teacher. My husband and I started noticing negative changes in our child after coming from school – she was using bad words, and she was not progressing in her personal development and independence. That was when I understood that we had to act and do something about our child.*

Informant, Daycare Center Riviera

At the beginning of operations, both NGOs started as rights-based organizations before transitioning to service-based organizations.

> *During the first years, we had to find a way of being registered. Nobody, including the legal system, knew what to do with us or how to register us.*

Informant, Daycare Center Riviera

> *In the beginning, we were working with only five children. We didn't know where to find children and families to work with. Our efforts went towards gaining legal and societal recognition. Today, we focus on the quality of care and reaching out to more families and children with disabilities.*

Informant, Karin Dom Foundation

The lack of official registers of families and people with disabilities encouraged both organizations to start collecting data and identifying families with disabled members.

> *There were foreign specialists who were coming and wanted to help us establish our organization. I remember them asking "Where are the children? We go out, and we don't see them.*

Informant, Daycare Center Riviera

Thus, one of the first tasks in building resilience was to make the children and families of people with disabilities visible to society. These endeavours took years and took place alongside efforts to sustain the work of the organizations.

> *The moment when we converted the organization into a service-based one was when we started to apply to different international projects for financial support and training. That was in the decade 1997–2007.*

Informant, Karin Dom Foundation

> *The local and governmental institutions were not there to help. We needed a model for social care to follow. The international projects were our solution. Through the projects, we were applying for funding, and we were learning at the same time. Today, we are where our foreign trainers were 20 years ago. But we are still happy with what we have achieved.*

Informant, Daycare Center Riviera

People with and without disability take part in a group activity, Daycare Center Riviera, Varna, Bulgaria.

"Welcome on board" – theatre scene, Daycare Center Riviera, Varna, Bulgaria.

The recognition and support that the organizations received through their participation in different projects established them as visible and innovative entities that could provide training and services. They learned through the successful practices of foreign organizations and adjusted the knowledge and skills gained to the needs of Bulgarian users. In the early 2000s, the Daycare Center Riviera and the Karin Dom Foundation were just as important for families with a member with a disability as a government institution would have been. Their services were of enormous importance in the city. They included informing families of their rights and providing services for disabled children, such as day-care services and family counselling.

Support from local and national authorities also fostered the process of resilience.

> *The local government was there to listen to our problems, but it was always rejecting our calls for support. After we established our organizational facilities – after we fought for our building and established our services and staff, they said: 'We will support you.' That was in 2008 when they started. They decided to support a working organization. Now we feel relieved that despite the little money that we receive, we are part of the local budgeting of the government.*

Informant, Daycare Center Riviera

During that same period, in the 2000s, the Government of Bulgaria also started supporting families with disabilities, particularly in the years prior to joining the European Union (EU) (2005–2007). Two years before joining the EU, the first disability bill was passed. This law highlighted the needs of children and individuals with disabilities.

> *That was the first recognition of the rights of people with disabilities. It was just the beginning.*
>
> Informant, Karin Dom Foundation

This national commitment to building resilience was a reaction to the challenges faced by vulnerable populations of people with disabilities. Such an alignment provided a framework for community resilience which increased community social ties and simultaneously improved dialogue with and trust in public agencies in a broader sense. For example, a programme that provided a personal assistant to people with a disability added to the discussion on providing assistance to elderly people.

Action during EU membership

An informant from the Daycare Center Riviera says, “Our mission is endless.” This is the belief that people involved in organizations serving people with disability have. For them, building resilience to increase the capacity to overcome the negative effects of disability, discrimination and lack of access to services for families with disabled children and to fight to change negative societal attitudes is a continuous long-term effort. The difficulty in changing people’s attitudes means that the process of resilience is an ongoing one, rather than a one-off initiative.

The process evolves over time and must constantly adjust to the changing but still negative and unsupportive social environment.

> *The most important thing is to change the attitudes of the public and of the medical professionals towards people with a disability.*
>
> Informant, Karin Dom Foundation

> *The change that we want to see is at school, at the hospital, in the playground, where people will not be afraid to accept and communicate with people with a disability.*
>
> Informant, Daycare Center Riviera

Creating disability inclusive environments and societies has to occur with the help of both the authorities and community partners (NGOs). The nascent field of community and organizational resilience builds on strong community cohesion, inclusion and social equity (10). Investing in culture and art programmes is one way both disability organizations have chosen to build inclusion in the community. They have the support of local authorities, but the breakthrough in changing people’s mindset has yet to happen.

Despite the ongoing and unsolved problems that surround disability, such as the absence of complete societal inclusion and persistent negative attitudes, the informants interviewed were very hopeful about the future. They see that their work is fruitful and benefits not only their children, but the community and society as well. Attitudes are changing, albeit very slowly. They have evolved as recognized institutions in society. They have paved the way to sustainable development in the field.

> *Now that we have started working for people with disabilities, we cannot stop. We started more than 20 years ago, and I believe there will be a continuation of what we do. Before, we were afraid of what would happen to our children after we died. Today, I don't have this worry anymore. I know that other mothers of young children with disabilities, along with all our friends, will continue our work for the good of children with a disability.*

Informant, Daycare Center Riviera

> *We have not only overcome the difficulties, but we have become models for others to follow. Today we are providing training for parents and professionals, and we are helping other NGOs to start their service. Today everybody in the region knows that Karin Dom means professional expertise and care. Those that have worked for us are known as experts in the field.*

Informant, Karin Dom Foundation

Lessons learnt

Bulgarian NGOs play an important role in strengthening resilience in children with a disability and their families. They provide a community-based platform for understanding the factors influencing resilience building and the capacities needed for a more inclusive society. Historically, research into the nature of resilience and disability was explored mostly in the fields of psychology and less in other social sciences fields (11). Research included risk and protective factors impacting on resilience. Resilient individuals were described as those having the assets and resources that enabled them to self-protect and overcome the negative effects of exposure to risk. However, attention to structural, meso-level factors, such as NGOs that could build resilience, was insufficiently addressed because research on disability has been primarily focused on the individual and the family.

Creating supportive environments for building resilience in people with disability should be done at every level of the societal structure: at individual and family level (micro); at meso level (civil, community and social organizations); and at a macro level (society and government). An essential layer in this resilience structure is the meso level which is the connecting, dynamic force between both micro and macro levels of resilience building. As observed in this brief narrative, risk and protective factors were present at every stage of developing disability services. These factors therefore have an impact at every layer of societal structure (micro, meso and macro). Using Bronfenbrenner's ecological systems framework, the findings in the study are conceptualized in the following ways (12).

Micro level

Many studies have shown the importance of family in promoting resilience. Factors such as stability at home, involvement in schooling and a stable socioeconomic environment have been associated with positive outcomes for people with disabilities. (13–16). A significant risk factor at micro level can be family composition and the structure of the family, i.e., single- or dual-parent families. As discussed by the case informants, family support, including support from the life partner, is essential in the early years of managing the negative effects of having a child with a disability. Strong family ties can provide financial security and emotional support and increase parental involvement (17).

Meso level

Meso-level factors refer to the social and civil resources available to families. The role of NGOs is emphasized in the disability resilience-building process. In their role of providing support through advocacy and service disability, NGOs act as a buffer against the effects of negative life events such as discrimination and social exclusion. By empowering people through knowledge and advocacy, disability NGOs, such as the two operating in Varna, help people with disabilities and their families to achieve better outcomes in dimensions such as education and health, and reduce their sense of voicelessness and powerlessness. Risk factors at meso level can be unsupportive community institutions and settings such as schools, hospitals and neighbourhoods which may not provide the environment needed for individuals and their families to feel fully included in society.

Macro level

Macro-level factors refer to economic, political and social factors and public attitudes towards disability. The protective factors identified at macro level, such as the positive pro-disability change in the legislative system of the country along with partial state involvement in the provision of services for children with disability, contribute to both individual (micro) and meso-level protection. Such legal procedures include a wide range of measures like social and income support and improved social policies. However, the greatest barriers at macro level yet to be resolved are attitudes and discrimination against people with a disability. As some of the informants have experienced as caregivers of disabled members, such barriers can be significantly associated with psychological distress and life dissatisfaction and can be directly related to depression and hopelessness (18,19).

In conclusion, achieving resilience for people with a disability and their families is a collective effort. Governments and civil–society organizations in Varna and in Bulgaria in general are making progress in strengthening resilience and creating supportive environments for people with disability. This implies greater social cohesion and increasing capacity for ongoing adaptation to adverse events. Ultimately only resilient societies can build a resilient future. The work of these two NGOs in Varna shows that helping disabled children and their families allows them to gain control over their life and build resilience despite challenging circumstances.

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Denmark. The Community Champions Network as an approach to increase local resources for health and resilience

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Abstract

This narrative aims to provide examples of local actions that create supportive environments for community health and resilience. The examples selected represent only one of many innovative actions undertaken within the WHO Danish Healthy Cities Network. The Network started the project The Community Champions Network in 2014 with 20 actively participating municipalities. The project comprises a diverse range of activities. The narrative indicates the impact of such activities in creating supportive environments for healthy ageing, gender and ethnic topics and other community health and well-being related matters. The overall aim of the Community Champions Network is to reduce health inequalities by using an open and inclusive approach to the co-creation of health, nurturing and developing health assets and the resilience of local communities.

Issue

In Denmark, the institutionalized national welfare state has a long dated legacy. Over the years, it has played a key part in raising people's life quality. With participation from workers' unions, employers' and a great degree of citizen involvement through associations, the welfare state lifted the average living standard of citizens and lessened social and economic inequalities. Nevertheless, health inequities do persist within Danish society (1). With a strong presence of institutionalized welfare state services and allowances, citizens may run the risk of becoming passive recipients of state services. Often the opportunity for citizens to be active participants in both the shaping and delivery of health and other welfare services is overlooked. In some situations, people can feel intimidated by the intervening approach from the public sector and are therefore difficult to reach with traditional health initiatives (2). Moreover, lonesomeness and isolation are key challenges for mental health and health inequities in Denmark (3).

The Community Champions Network attempts to address these issues with a so-called co-creation approach. The term co-creation or co-production indicates an approach where professionals and citizens take innovative action to make better use of each other's assets, resources and efforts to achieve better health and well-being outcomes. This project tries to create sustainable health initiatives and supportive local communities through citizen involvement by means of co-creation processes. It aims to empower people to take part in their community and enhance their level of inter-connectedness and control over decisions affecting their own health and the well-being of the community. This approach fosters a sense of belonging and creates supportive environments for health, including mental health. These are indeed key elements in a process of resilience building.

The benefits of the approach are related to the fact that citizens often know things regarding the health and well-being challenges and opportunities of their community that professionals do not necessarily know. Community members may have diverse capabilities and talents which they can share with professionals and other citizens. Community members can be seen and utilized as *community asset holders*. Thus, if properly supported, citizens can engage in collaborative rather than paternalistic relationships with welfare institutional staff. They can collaborate with other service users and with other members of the public to bring out the best in them benefitting the community as a whole (4).

A key point in The Community Champions Network is to view citizens as active participants with information and experiential resources that they are willing to invest to improve their own quality of life and into helping others, rather than as passive clients waiting to be helped. This approach tried to reach people that are usually not easy to reach and keep them in the loop through social engagement. By building resilient communities and strengthening the well-being of citizens, they might not need to become passive clients of the public sector. The aim is to ensure that people have a chance to be active participants in their society and become more resilient and in control of their life and destiny.

Action

This subsection outlines the main actions undertaken within the Community Champions Network together with some examples that highlight bottom-up approaches to strengthen resilience. The project aims to overcome some of the drawbacks of conventional approaches to the delivery of public services. Usually, conventional approaches describe communities in terms of their problems. People and communities are defined by their deficiencies (5). Public services set out to fix problems for individuals and communities and, in doing so, they run the risk of taking away control from people by making them passive recipients of services. Evidence suggests that a sense of control over one’s life is associated with better health and a greater likelihood of adopting healthy behaviours (6). Undermining that sense of control can be very damaging as it can increase passive acceptance of risk (7). It is not particularly surprising that people who are consistently told they are living deprived, hopeless lives tend to respond with passive acceptance (8). The outcome is an increasing dependence on services provided by others. This is what the Community Champions Network wants to change.

Better ways of working are needed to avoid health and social inequalities continuing to widen. The co-productive approach through the Community Champions Network is designed to contribute to identifying and nurturing the protective factors that support health and well-being. The actions undertaken within the Network are bottom-up efforts that promote the self-esteem and coping abilities of individuals and communities. The actions undertaken so far have been mostly part of spontaneous community initiatives where local connectedness, solidarity, warm relationships and mutual respect have been key ingredients for development and progress. One example is Brøndby Beach where a cafe offering community assistance was opened beside the local supermarket. Many spectators were curious and stopped by, with several local residents offering to get involved in the initiative. Elsewhere, local community champions initiated physical activities in a courtyard in Sydhavn, Copenhagen; local residents whose profiles spanned age, gender and ethnic groups eagerly participated and took ownership of the project. As in various other participating municipalities, this created cooperation with relationships and identities that exceeded the formal structures and roles.

To show the diversity of action undertaken within the Community Champions Network, a number of selected examples from participating municipalities are outlined below.

Assens municipality: combining integration and health through social communities

In the city of Assens, the municipality decided to reach out to the local Red Cross in its objective of combining health and integration. This was a gateway to a group of female immigrants and refugees who had been requesting a place of their own, where they could freely meet and do activities. Approaching the wishes of the group with an open mind, the municipality arranged space in a local nursing home, which has facilities to make a shared dinner, do physical activities and be connected in a number of ways. The group of women meet weekly with two health workers and two Red Cross volunteers, and the meaningful connectedness is evident. The women contribute to the planning of the activities, as well as expanding their network in this new country. Before this experience, they would often keep their distance from public health workers, as there was a cultural and language barrier.

This project enabled women to enter a community of like-minded others, while making it possible for the municipality to get in touch with a group of citizens that are often difficult to reach. It was an eye-opener to combine integration with health, especially through the Community Champions Network project. Many immigrants and refugees are not used to the public sector organizing or facilitating their social activities. They may perceive this as being more monitoring and control rather than a service. However, as this example shows, by having the municipality acknowledge the women's wishes and give them ownership, misperceptions can be avoided, and co-creation of a relaxed and comfortable environment for future contact with the municipality has been fostered.

Holbæk municipality: local health communicators

As a first step, a health worker from the municipality was stationed in a social housing area to create a visible and accessible link between citizens and the municipality. The worker additionally tried to do research on the needs and wishes of the residents for future activities in the area. By conducting a door-to-door survey, the health worker gathered ideas and support for new activities. The first initiative was a running club, where people met and went for a run in an informal relaxed social gathering. It started as a walk-and-talk club but after a few weeks, participants ran a few kilometres, and later on took part in a local race with their entrance fee funded by the municipality.

The process set in motion a kind of domino effect. Besides starting to exercise, participants increased their willingness to socialize and engage in the local community. There came to be a sense of unity and belonging within the group. Moreover, health professionals from the municipality recruited six community champions, who participated in a course on health and information. This allowed them to gather specific knowledge on the types of public health services and other resources available locally, which they could pass on to their neighbours and other local residents when engaging in talks and activities. In this way, health became a casual talking point among like-minded individuals rather than a lecture from health professionals. The health worker from the municipality and the community champions co-create active citizenship among the whole community by engaging people on their own health – both physically and mentally. Besides bringing more awareness about one's sense of well-being, it revived the connection between municipality and citizen, making it closer and more trustworthy.

Vinderup, Holstebro municipality: citizen involvement

The village of Vinderup faced a problem. In 2008, the municipality built a leisure area for the young people of the village. Its objective was to become a gathering point where different kinds of activities could take place (handball, basketball, football, skating, etc.). Therefore, they covered the area with cement to flatten the ground, but the area was never used. With the Community Champions Network project, the municipality decided to address the issue differently by combining efforts form the health and youth departments. They reached out to

Stefan, a local social worker from an afterschool centre, who had close contact with the local youth. Using him as a gate keeper, the municipality started a citizen involvement process. This created close contact between local government officials and the young people who were supposed to use the area. The officials learned that a proper football field was of more use than a skate area, so they renewed the area into a more natural gathering spot for young people. This open approach set the groundwork for future active citizen involvement as the municipality expressed both accessibility and openness toward the local community.

Sydhavn, Copenhagen municipality: health promotion through community building

Copenhagen municipality collaborated with a social housing block in Sydhavn. The area is affected by a high level of unemployment, many recipients of public support and a large concentration of vulnerable citizens with social and/or mental challenges. The objective of the project was to reduce health inequities by getting in touch with residents who normally would not make use of public health services. This was to be done by strengthening the community feeling of the housing block and rebuilding trust with the municipality. Health professionals worked as catalysts and invited residents to contribute with their ideas of shared activities. Plenty of initiatives were started – a court yard project, urban gardening, communal eating, flea market, health check, sailing trips, a community choir, etc. They were all voluntarily started and driven by residents.

Despite some contrasting ideas about running a housing association, the positive effect was that many citizens showed a passion and willingness to contribute to the community. The municipality learned how to facilitate rather than dictate already-made top-down solutions. This made space for the residents to take charge of their own community and allowed co-creation to blossom. The support for their ideas also helped them to trust the system. This collaboration could make it easier for vulnerable citizens to approach public health services in the future.

Dalmose, Slagelse municipality: all about co-creation

The objective when engaging with the Community Champions Network was to strengthen the sense of community in the village of Dalmose. For some time, there had been a group of volunteers in the village. This was a group of retirees who had a great passion to take part in different activities in the village. With the new project, they became community champions, which changed their own and the community's understanding of them. Meanwhile, local associations and businesses were invited to a working group to assure support all around the village.

The main initiative was a café, where activities and events could be arranged. One of the activities was communal eating with the theme "Pensioners Also Make Pizza", where families could eat dinner on busy weekdays on the way home from work. It helped to build a bridge between generations. It allowed new relationships to blossom, which was an important factor in the process. The citizens saw the benefit of getting involved with the support of the municipality. Despite being economically dependent on the municipality; the cafe and the local activities were all driven by local volunteers. Co-creation really worked in this process. The municipality simply facilitated the structures for the local community to grow, but it was all managed and driven by the community itself, which makes it a sustainable co-creating initiative.

Roskilde municipality: one woman's passion benefits a whole community

Jeanette is a passionate woman who became an inspiration for women in her community in her role as community champion. She found her passion when attending a Zumba-class arranged by the municipality's health department. She was inspired to establish a fitness class for women like herself who want to do physical activities, but do not want to join or cannot afford the cost of a gym. Health professionals saw the potential and supported Jeanette in starting a fitness and relaxation class. Even in this case, a domino effect happened. After some time, the fitness class evolved into a social gathering for many participants who otherwise would not get involved in the community. Jeanette became a link between vulnerable citizens and the municipality's health department.

Impact

The Community Champions Network in Denmark has had a great impact and has been inspiring actions throughout the country, and more municipalities are getting involved. In the health sector, it has helped to reframe the work and know-how of health professionals. It has contributed to increasing openness to alternative approaches, especially when engaging with citizens that are often difficult to reach. The project also brought attention to mental health and its connection to physical health and the need to avoid isolation and stigmatization.

This project resulted in many examples of engagement in local communities. People who proved they have the energy, resources and the will to contribute with activities and support for their neighbours joined in and become involved in their community. Though health was the thread of consistency throughout the project, it was not always the starting point for local activities. Health includes mental health and this project encouraged participation and socializing. The project provided social environments focusing on local resources and seeing the citizens' potential rather than pointing out, or even worse, stigmatizing their deficiencies.

Local citizens were given the opportunity to become community champions who benefitted greatly from participating in the project, as did the community benefit from their engagement. This was well expressed by a community champion during the project:

> *Before I got involved with the WHO Danish Healthy Cities Network I wasn't well. I was born with a brain injury and have been through a lot of things, but the network believed in me, and gave me areas of responsibility that made me grow personally. It led to a point where I could take more responsibility for voluntary work. I became a community champion and I started a social bicycling team, where we meet every two weeks and cycle 15–20 km. We usually take a break in a natural setting where we can talk and get to know one another. It improves my life quality to do good for others; it's a joy and it gives me a lot as a person. Thanks to the network, I have the drive to do my activities today.*

Lessons learnt

The experiences and the reflections of the project are many. They help to make progress and succeed with sustainable co-creation initiatives to reduce health inequalities and support action for resilient communities. Below are some key lessons, which can provide guidelines for those, particularly health professionals, who want to engage in co-creating initiatives.

Listen and learn.

One of the greatest challenges for engaged health personnel to be helpful in a co-creation approach is to relinquish control. They must rely instead on how to become supportive resources and equal partners in the issues which affect the health and well-being of the community they serve. With this approach, the goal is to help people to help themselves. This is realized by asking more questions to understand the specific context of people's lives and the potential they have, rather than giving ready-made standardized answers. It is related to the idea of empowerment, where officials and health personnel facilitate a process by which citizens are enabled to negotiate the resources they need to take better control over their own lives.

The co-creation approach focuses on proximity and relations. When engaging in interactions and activities, it is always important to be interested and appreciative of community lay resources by making them relevant. Both the starting and ending point should be the health and well-being of citizens and the reduction of inequities. Extensive efforts should be put into personal contacts and relations, instead of expensive general large-scale surveys. The vision has to be clear and ensure that public services are built around citizens and communities, their needs, aspirations, capacities and skills, and work to build up their autonomy and resilience. Health professionals are an instrumental element of this process, not a barrier to it. That is the essence of the approach used in the Community Champions Network. The experiences from the Danish municipalities reveal that local citizens often miss activities and the sense of belonging to a community. Health and welfare officials should help to reverse this.

Look for passion.

Everybody wants to belong, to do something for others – even people who might look like they are in need of a helping hand. The main health action is to activate their motivation to do something. It can start small and build up. The role of the health professional becomes a facilitator for development by building relations and showing opportunities that strengthen the citizen's role in the local community. A great challenge for the local community worker is for health professionals to find out what people need instead of telling them what they need. Otherwise, citizens may become passive and lack ownership. The philosophy of the Community Champions Network is that resilience derives from the passion of the contributor, in which the citizens can identify with the activity.

Keep it simple.

It is important that local community workers facilitate cooperation with citizens by avoiding professional jargon in favour of common language. Keep activities simple so everyone is included.

Enable instead of serving top down.

When enabling new local actors to do co-creation activities, they need facilitation and support instead of rigid management, top-down guidelines, regulations and standardized procedures. The need to let citizens take the initiative may represent a complex development process for many professionals. The strong vision to enhance the lives of citizens often leads to top-down serving rather than enabling, which leaves out local ownership and passion. Rather, the focus should be on the citizens' will and passion so they can become contributors and not just passive users. This is essential in order to enable local activities to develop through local assets and impact on the creation of resilient local communities.

Be bold.

Bold managers and professionals are needed to pursue a co-creation approach to community health, well-being and resilience building. Boldness to step away from the traditional professional identity and boldness to walk into unknown territory without assured outcomes and effects is not an easy undertaking. On the other hand, engaged professionals know that new approaches are needed to address issues of community health and health inequities. This Danish project of co-creation was fortunate to have professional and community members that had the courage to try new approaches. With more people and institutions engaged in co-production of health and reduction of health inequities, a scientific literature of evidence and impact will consequently grow. This is a much needed process of change for making real progress in tackling the issues of health inequity in society.

Be patient.

It is difficult to reach people who are outside of the country's social systems. A consultant from a participating municipality observed that making new relations is difficult but necessary for co-creation. Recruiting people who are used to being passive recipients of public support takes patience. It takes time for citizens to feel comfortable, develop trust, show passion and courage and become fully engaged as main actors in a co-creation approach. In the end, this patience is rewarded with joy, pride and courage when community champions make their resources available to others. At a conference marking the end of the project, all community champions received a medal for their contribution. Everyone present experienced what a healthy and resilient community is all about.

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United Kingdom (England). A social movement for health and resilience in Blackburn with Darwen

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Abstract

This example shows how public health institutions can embrace the contribution of a wide range of community groups and social movements as a strategy for health improvement and resilience building. It shows that through strong leadership and governance it is possible to utilize and nurture assets within communities, promoting equity and increasing people's control over the determinants of their health and lives. The example is helpful in addressing the challenge and seizing the opportunity to incorporate a bottom-up approach, and effectively use the assets from the diversity of grassroots community organizations existing in a given geographical area. As such, local public health authorities of this part of England took actions that offer important lessons on how resilience can be strengthened by supporting and allowing diverse groups to thrive together.

Issue

Blackburn with Darwen, a district in the northwest of England, comprises the two towns of Blackburn and Darwen and the surrounding countryside, including numerous small villages and hamlets. A cradle of the Industrial Revolution in the 18th century, the area was once a thriving borough of cotton mills and textile factories, briefly known as the weaving capital of the world, with more than 140 working mills at its peak. Like many of its northern neighbours, Blackburn with Darwen has however faced a steady decline since the collapse of its industries, and its population of almost 150 000 now resides in one of the most deprived regions in England. As such, Blackburn with Darwen exhibits many of the health and social problems associated with high levels of deprivation.

Health policy and funding in the United Kingdom both currently remain focused primarily on individual-level interventions, prioritizing the treatment of illness and hospital-based care over prevention of illness and the creation of health. Yet the challenges to health and well-being faced by Blackburn with Darwen and other post-industrial towns stem from long-term and deep-seated structural and societal issues, and cannot simply be "treated away". Blackburn with Darwen exemplifies the need to stop investing only in the wrong end of the problem. Instead the aim is to address the underlying risk conditions; to take a population-based approach to improving public health and well-being; to shift focus from treating illness to preventing it; and to build resilience at individual, community and system levels.

While Blackburn with Darwen exhibits many of the social and public health issues typical of areas that experienced post-industrial decline, it is also a district with a great many strengths. They include: strong community networks; effective political representation; a fantastic range of voluntary, community and faith organizations; and, most importantly, its residents. Harnessing the passion and energy of residents is crucial in driving the changes that people want and need, and Blackburn with Darwen is taking a social movement approach to improving the health and resilience of the local population (1).

Residents in Blackburn with Darwen participate in outdoor, community-based activities.

Action

This narrative focusses on a particular type of action: action through social movements for health.

Social movements involve collective action by individuals who voluntarily come together around a common cause. They put pressure on society to change, respond directly to the needs of people and communities and have the potential to spread widely across populations. Social movements can have tremendous power, and have led to transformational changes in both practice and culture (for example, the civil rights movement).

Social movements are integral to a healthy and thriving society. When successful they can enable disproportionately positive outcomes. High levels of social movement activity indicate a particular set of factors are present within a community: an engaged citizenry, a diversity of movements, high mobilization around common causes, and/or significant grievance with the current state of affairs (2). These societal features enable movements to be born and to grow.

A social movement for health specifically refers to "a persevering people-powered effort to promote or resist change in the experience of health or the systems that shape it" (2). The HIV/AIDS movement has, for instance, transformed the way people experience their own condition and has created a cultural shift in how society responds to those with the illness and to issues of sexuality more generally (3).

Of course, social movements are not an answer to all health and care concerns. The histories of the examples above demonstrate that while social movements can be powerful forces for change, they are also unpredictable, turbulent and risky, often causing conflict with institutions and power structures. Yet, social movements have the potential to be a key resilience-building concept in line with Health 2020 priority area four (creating community resilience and supportive environments for health), with action that can be applied at all levels: individual, community and system. Social movements therefore represent one approach to the system-level transformation so urgently needed in health and care (2). If successful, it can have significant health impacts by:

1. bringing about change in the experience and delivery of health care
2. improving people's experience of living with disease, disability or illness

3. promoting healthy lifestyles
4. addressing wider determinants of health
5. democratizing the production and dissemination of knowledge
6. changing cultural and societal norms
7. bringing about new health innovation and policy-making processes.

The potential of social movements to drive widespread and active creation of health, in contrast to the traditional, narrower focus on treating disease, means it makes sound economic sense to invest time, effort and resources in finding local solutions to help social movements to emerge and to spread. As part of their strategy to build and strengthen both individual and community resilience, the Public Health Department of Blackburn with Darwen Borough Council aims to harness the energy and emotion of social movements, rather than resisting them, in order to encourage the adoption of new social norms and ultimately to have a meaningful and sustained impact on the health of the population. Professor Dominic Harrison, Director of Public Health for Blackburn with Darwen, states that health as a social movement is "a process of allowing and enabling a community to take action on the determinants of their own life chances".

The public sector is uniquely placed to help create the conditions and make the space for social movements to flourish. Whether and how social movements achieve their aims depends in part on the ability of institutions to listen and effectively respond. To fully realize the transformative and innovative potential of social movements, institutions need to be agile and responsive, with a commitment to engage and create more effective ways of doing things for the benefits of population health and reduction of inequities. The Marmot Review (4) made the following recommendation.

> *Political, civic and managerial leadership in public services should focus on creating the conditions in which people and communities take control, to lead flourishing lives, increase health expectancy and reduce disparities in health expectancy across the social gradient.*

New working practices and models of engagement are required that take advantage of both the efficiency and scale of institutions and the dynamism and agility of social movements. For this to occur, two things are required: a willingness to change the culture and working practices within organizations; and better connections with empowered local communities, who are capable of demanding their voices be heard. The vision of the Public Health team (1) is therefore for Blackburn with Darwen

> *to become a place where social movements are encouraged and enabled to thrive, through close collaboration between empowered residents and responsive institutions, for the improvement of health and wellbeing.*

To harness the agility, freedom, positivity and determination associated with social movements, the team is therefore actively developing these attributes within its own organization and the wider community using a change-making approach, which recognizes that the underlying culture, norms and expectations of organizations and the communities they serve are of far greater importance than organizational structures (5).

Embodying such an approach is the first step in changing the ethos and norms of the institutions and communities that create Blackburn with Darwen. There is now less focus locally on formal structures and much more on developing a positive working culture, shared values and common purpose by encouraging three change-making values: creativity, self-determination and collaboration (5).

Creativity is valued within the team as a way to prevent inertia and to drive innovation; ideas are not considered merely as something that comes from senior leaders. Employees are given freedom to practice self-determination, a licence to act on their own initiative and to try new approaches without seeking explicit permission. This freedom to act has led to many staff pursuing projects outside of the statutory work of their department, including the redevelopment of community green spaces in collaboration with local resident groups.

Finally, effective collaboration is helping to counter the fragmentation and territorialism characteristic of the English health system, in which health-related services are split across a great many organizations and sectors who often work in silos. Effective collaboration and partnership building is breaking down these barriers, allowing better integration of health and care services and ensuring that effort is reinforced rather than duplicated across the region. For example, the Public Health team have developed the Place-Based Prevention Framework as part of a larger plan to transform health services in the region (6). The Framework explicitly advocates a whole-of-society approach in which every individual, community group, neighbourhood and locality agree to work together to promote good health; and where every organization (voluntary, private and public), management group, governance system and decision-making body are mobilized to support good health for all.

By embedding these change-making values of creativity, self-determination and collaboration into their own working culture, the Public Health team now share and extend these values to partners and local communities, thereby helping to create the conditions necessary for social movements to thrive.

Connected and empowered communities are healthier communities (7). Building community resilience, emphasizing and developing positive community assets – and not focusing only on problems and needs – goes hand in hand with achieving large-scale change and successful social movements for health (8). The Blackburn with Darwen team recognizes the role of the public sector in enabling people to act for themselves. To create an environment conducive to social movement development and growth, new ways of working with local communities are being fostered with collaboration and coproduction becoming routine.

A number of approaches are being taken, including: recognizing people as assets, with knowledge and skills, as well as needs; developing strong and sustained networks, recognizing the importance of shared learning; developing approaches that are community led and better at connecting people to their communities; creating healthy places that build social capital; and commissioning in a way that reflects the concerns of local communities and values co-production.

Blackburn with Darwen is now putting the thinking behind social movements into practice. Two examples of this approach in relation to adverse childhood experiences (ACEs) and the commissioning of substance misuse services are outlined below.

Impact

In order to describe the impact of the approach adopted in Blackburn with Darwen, two examples are given.

The first describes the issue of embedding social movements in addressing adverse childhood experiences. ACEs is a term encompassing 10 stressful or traumatic experiences that children can be exposed to while growing up, ranging from those that directly harm a child (such as physical, verbal or sexual abuse, and physical or emotional neglect) to those that affect the environment in which they grow up (including parental separation, domestic violence, mental illness, alcohol abuse, drug use or incarceration). ACEs are strongly associated with a range of chronic illnesses (diabetes, heart disease, etc.) and health-harming behaviours (smoking, alcoholism, violence, incarceration, etc.) in adulthood (9,10). The promotion of safe, stable and nurturing environments and relationships is of fundamental importance both for the primary prevention of ACEs and to mitigate their effects in those who have suffered them, by providing a buffer to the effects of childhood stress and trauma and a foundation for building resilience (11).

The ACEs movement has so far been led primarily by professionals, and the Blackburn with Darwen Public Health Department has been at the forefront locally and nationally of raising awareness of ACEs and their impact among those professional groups most well placed to have a positive impact, including the health, educational and criminal justice sectors (12). While this has been a crucial first step, in order to really drive the ACE prevention agenda forward, new approaches are being explored with the aim of involving and inspiring local communities to become aware of ACEs and their impact, realize the potential of their own communities in tackling ACEs and to become committed to achieving positive change.

A citizen-led movement will bring ACEs into the hands of local people and communities, helping them make sense of their experiences and current behaviours and to advocate for system change. Activism at a local level, alongside system-level change, is needed to strengthen the response to ACEs, and this is the approach currently taken in Blackburn with Darwen.

By their nature, it is not possible to predict the exact ways in which movements emerge and evolve, but this can include creative, emergent, experimental and non-institutional strategies and tactics, formal and informal networks, activism and the creation of physical and digital spaces. In Blackburn with Darwen, a variety of mobilization and movement-building activity for ACEs is being progressed including:

- innovation summits designed to foster creative thinking around the issue of ACEs, build awareness around ACEs and start to co-develop pilotable interventions with people who could contribute their direct experiences in their implementation;
- screenings of ACE films *Paper Tigers and Resilience* to help build momentum for and narrative around the ACE journey and to reach the widest possible audience;
- neighbourhood-level citizen-led events to build on the energy and outcomes of the innovation summit, to instigate debate and help to identify innovative solutions at a local level;
- developing local, regional and national formal and informal networks, coalitions and communities of interest, to grow the conversation and help build solutions; and
- an ongoing programme of celebration and learning to capture and understand where and how change is happening.

The second example focuses on embedding social movement approaches to address the complex issue of substance misuse. There is strong local evidence that recovery from drugs and substance misuse is best supported by peers, allies and community action, and Blackburn with Darwen has therefore actively encouraged the growth of a social movement in relation to their substance misuse services. When the Council tendered for a substance misuse service provider in 2014, they required bidders to adopt the Recovery-Orientated Integrated System model in which those with lived experience were involved in raising awareness, reducing stigma and promoting prevention. Key to this were coproduction and the development of community-based assets, including: working collaboratively with local people and wider stakeholders to ensure that services truly meet the needs of people and their families; building on individual strengths; assisting people to achieve their life goals; and promoting overall improved well-being for all.

© Blackburn with Darwen

Using art and design to build key messages and build social movements for health in Blackburn with Darwen.

A voluntary sector organization was appointed and has provided substance misuse services across Blackburn with Darwen since 2015, including education and prevention, training, treatment and recovery support through easy access support to both young people and adults. The effectiveness of the system has been enhanced by new and improved relationships between professionals, citizens and volunteers and with schools and colleges, local businesses and employers, and other voluntary, community and faith sector organizations.

There have been numerous positives from using this model. Many service users are engaged and connected through regular sports and social activities including football, boxing, fishing, walking, choirs and family craft sessions. There is now a regular community sports day, participation in the nationwide Recovery Walk, and health and nutrition classes that provide cooking and lifestyle skills. In addition, residents are given the opportunity to learn a skill or gain further qualifications and help is provided to get users into apprenticeships and employment. All of these activities help those affected by substance misuse be more confident and sociable, stay connected and understand that they are not alone with their situation.

A key part of the model's success has been enabling and empowering residents to take action for themselves, with many now regularly leading projects or getting involved in mentoring others. The Step Up buddy system utilizes peer mentors to ensure a wealth of experience and support for those leaving treatment.

As a commissioner, Blackburn with Darwen Public Health has not dictated what needs to be done, but instead allowed and encouraged the voluntary sector and the community to mobilize and organize specific services and broader well-being projects which are most relevant and beneficial to them. This is a prime example of how powers can successfully be relocated away from statutory organizations and towards citizens, to empower them to take ownership of their own recovery and to tackle substance misuse more widely.

Lessons learnt

Social movement thinking is beginning to bear fruit in Blackburn with Darwen, both in terms of changing working cultures and how health professionals engage with and respond to the public. The Public Health team, however, acknowledges that it is still very early, and the potential scope of social movements for health is much broader than the examples provided above. Almost every aspect of health and well-being could be influenced for the better by a demand for change led by residents, including housing, transport and education alongside traditional health systems.

There have already been challenges. Social movements cannot be easily quantified or measured and often do not connect effectively with health services, without the movement either collapsing under the burden of bureaucracy or being pressured to change (2). The Blackburn with Darwen Public Health team's approach of actively encouraging health social movements also contrasts with the general history of social movements, which often flourish through conflict with institutions and power structures rather than because of support from them. There are few examples of public bodies seeking to actively create a demand to change their own practices, which is what Blackburn with Darwen is hoping for by enabling and encouraging local movements for health. Yet this reflects the thoughts of the team: that public health should be done with and for communities, not to them. As Professor Harrison states: "we must always remember that the Public Health department is commissioned by and for the community. It is the public that is asking and informing the Public Health department's actions".

The Blackburn with Darwen Public Health team is well placed to provide the initial spark for local movements, but acknowledges that the long-term success of this approach will rely on local people and communities taking ownership of movements from the very beginning, in order to drive the changes they want. The team is ready to listen, to adapt and to support nascent movements. Importantly, they are also prepared to let go and allow movements to take their own course, however unpredictable they may prove to be.

More information on social movements for health in Blackburn with Darwen and its work is available online (1,2).

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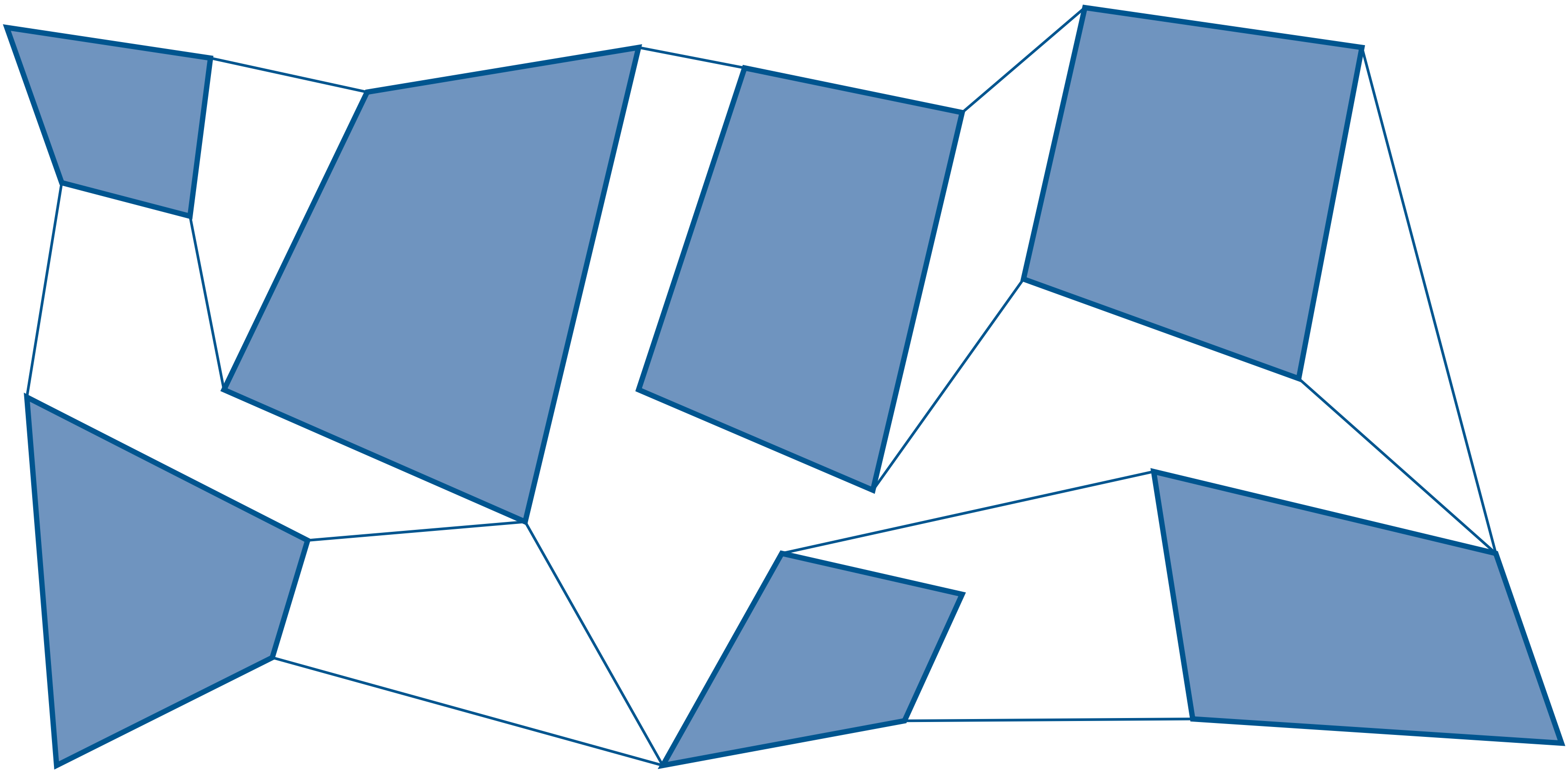
Part 4. Strengthening resilience at system level, both nationally and locally

Resilience is the result of a combination of assets, capabilities and positive adaptation and anticipation of opportunities that can be beneficial to health and well-being. System resilience is the capacity of organizations to transform their structure and means of operating to better address present or anticipated changes and uncertainties. It is the capacity to change when existing policies and practices are obsolete, ineffective or untenable. The inspirational examples under this heading show that systems at national or local level can change to better serve society and foster resilient citizens and communities.



Republic of Moldova. Introducing the HPV vaccine: the need to strengthen resilience at multiple levels

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Abstract

This inspirational example describes the action undertaken in the Republic of Moldova to facilitate the uptake of the human papillomavirus (HPV) vaccine. It highlights the main expected and unexpected challenges that the introduction of this new health measure had to address. The example shows how the four major resilience capacities known in the literature as adaptive, absorptive, anticipatory and transformative needed to be strengthened to obtain desired outcomes in this complex domain.

Issue

Since the development of the first vaccine, misperceptions and suspicions about vaccines have existed. A variety of health events and symptoms have been perceived as reactions to the vaccine; rightfully in some cases, wrongly in others. Responding to these events is a continuing challenge for health authorities as they potentially can lead to an erosion of public confidence in (all) vaccines and in the authorities delivering them (1–4). National immunization authorities need to work continuously to foster population anticipatory and absorptive resilience against vaccine rumours and scares. They also need to sustain strong immunization programmes that have the necessary adaptive, absorptive, anticipatory and transformative resilience allowing them to anticipate, respond and minimize the damaging effect of any event and prevent it from escalating into a crisis.

New vaccines pose even greater challenges as new health interventions are always the subject of more public attention and scrutiny than routine measures. The risk of mistakes or misperceptions on the side of vaccine providers to whom the vaccine is new is also increased. If the new vaccine has already been the subject of controversy in other countries, the need to build programmatic and public resilience becomes all the more critical.

In 2017, three middle-income countries in the WHO European Region planned to introduce the HPV vaccine among young girls to prevent cervical cancer; one of them was the Republic of Moldova (Box 4.1). This happened at a time where controversies related to the HPV vaccine had posed extraordinary challenges to otherwise strong national immunization programmes in other countries, most notably in Colombia, Denmark, Ireland and Japan. Highly publicized resistance was shared around the globe, driven also by social media. This resistance occurred despite scientific proof that this vaccine can prevent a deadly type of cancer, and that its safety and effectiveness are backed up by an increasing volume of solid evidence.

It was in this context that countries with weaker health systems, more vulnerable populations and less capacity to respond to vaccine safety-related crises were now introducing the vaccine. This warranted extraordinary measures to foster resilient populations and sustain resilient national immunization programmes, building on the hard-earned lessons from other countries. At the same time, this effort needed to take into account the limited resources available in the countries, as well as the time constraints from a donor requiring introduction of the vaccine within a certain time limit.

Box 4.1. HPV

HPV is a group of viruses that infect the skin or various mucous membranes (such as in the mouth or cervix). The majority of infections are not harmful, but common types of HPV can cause genital warts, cervical cancer and other diseases. HPV is the most common sexually transmitted disease. About 80% of men and women will become infected at some point in their lives, and it is especially common among sexually active men and women up to age 25.

Depending on which HPV vaccine is used, it will protect against the types that cause 71–90% of cervical cancer cases and up to 90% of genital warts.

Action

Experience from countries with consistently low or rapidly declining HPV vaccine coverage showed that some national programmes had been unprepared for such resistance against the vaccine, especially since the vaccine achieved high coverage and great success in its first years (5). Other factors that played a role in declining coverage included a lack of coordinated and rapid communication response, vocal anti-HPV vaccine advocates, misinformed media and vaccine safety concerns among health workers.

To prepare for the introduction of the HPV vaccine in the Republic of Moldova, a concerted effort was needed to take into account these challenges and build the necessary resilience at programmatic and population levels. Human and financial resources, however, were limited, and time was an issue as well. The answer was rapid formative qualitative research with key target groups, conducted by local staff (immunization programme and School of Public Health Management), to inform the development of a HPV vaccine introduction communication and contingency plan.[24]

Using qualitative research to prepare for a new vaccine was previously unseen in the country. However, achieving insights into barriers and motivators, existing knowledge and (mis) perceptions, as well as preferred messages and communication channels, was necessary to foster resilience among the girls who were to receive the vaccine and their parents. Understanding the health worker perspective was equally necessary to plan measures to build resilience in the service provision – through ensuring correct knowledge and addressing possible concerns.

In the national context, such studies are normally conducted by external, often international consultants. The fact that national staff conducted the research allowed them to limit cost, ensure a more rapid process and build capacity in the programme. Following training and ongoing support from WHO, a team of staff from the national immunization programme and School of Public Health Management conducted all formative research activities, leading to capacity building, ownership and a genuine understanding of the barriers to and drivers of the HPV vaccine among the key target groups. These actions were key factors in building anticipatory and transformative resilience.

The concrete outcome of the formative research was a report with conclusions and recommendations. Building on this report, a number of actions were undertaken (Table 4.1).

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[24] HPV vaccine introduction planning was multifaceted and included a number of measures beyond the activities described in this narrative.

All activities were developed and shaped based on the outcome of the formative research and aimed to build resilience among key target groups. Activities were implemented as planned, and the HPV vaccine was introduced on 5 December 2017.

Table 4.1. HPV introduction activities implemented in the Republic of Moldova based on the formative research

Target group	Activities
General	Communication plan, crisis communication plan, and contingency plan with clear roles and responsibilities across involved national institutions Vaccine website including HPV materials, segmented information for caregivers and health workers Facebook page with opportunities for questions and rapid replies Questions and answers package, segmented per audience Online and offline partnership with a parent organization Ask Mom, one of the largest and most popular online forums for parents Post-introduction assessment and support for districts with low HPV vaccine coverage Engagement of spokespersons (including prominent journalists and bloggers) that appeal to the target groups
Vaccine providers	Training, including session on engaging in dialogue with hesitant parents and how to deal with media HPV guidelines including questions and answers Booklet including interpersonal communication case examples
Parents and girls	Social media engagement through strategic partnerships with popular bloggers and a parent organization Ask Mom Video statements from doctors and celebrities based on formative research, concerns and questions raised by mothers Flyers, infographics and questions and answers developed based on outcome of formative research HPV video in health care institutions
Teachers	Partnership with the youth-friendly-health-services centre Neovita and the network of peer-to-peer educators Briefing note on the introduction of HPV vaccine for all pre-university facilities, together with the Ministry of Education, Culture and Research
Media	Mass media workshop on HPV Media kit for journalists, including questions and answers package and list of experts to ensure accurate and valid perspectives in the media coverage Press conference Established relation with key journalists before the introduction of HPV vaccine Positive stories about the HPV vaccine Systematic monitoring of mass media with evidence-based feedback in case of misinformation
Other stakeholders	Conference with national and international experts targeting leading health professionals and medical academia to present and discuss updated information on the burden of HPV diseases and efficacy and safety of HPV vaccines, and to respond to questions and concerns Stakeholder meeting targeting nongovernmental organizations, health professional associations, representatives of medical academia and health promotion and social media bloggers to share and discuss the HPV vaccine and planned introduction activities, demonstrate the importance of collaboration and build partnerships and support to HPV vaccine introduction


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Representatives of nongovernmental organizations, health professional associations and medical academia, and health promotion and social media bloggers attend a stakeholder meeting to discuss the HPV vaccine communication plan.


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Participants of the youth-friendly-health-services centre Neovita, a nongovernmental organization that supports and encourages vaccination against cervical cancer, attend a training session.


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Teachers take part in a focus group discussion in the Republic of Moldova.

Impact

The objective of the effort was to achieve and maintain high HPV vaccination uptake. To accomplish this objective, it was necessary to build resilience at all levels: a strong programme with efficient planners, knowledgeable vaccine providers and a population that was satisfied with the guidance, information and services received. Table 4.2 describes how the preparedness activities built adaptive, absorptive, anticipatory and transformative resilience (6) in an interplay between programme, population and service provision levels.

Table 4.2. How HPV introduction preparedness built resilience in the Republic of Moldova

	Programme	Population	Service provision
Resilience	Legislators, decision-makers, national and subnational managers	Parents, young girls, media, communities, opinion leaders	Vaccine providers, scientific community, research institutions
Adaptive	Messages, actions and preparedness activities for HPV vaccine introduction were fundamentally revised after conducting formative and eye-opening research.	Formative research allowed for the development of appropriate actions that clarify uncertainties in the population and build public acceptance and trust in vaccine use and safety, hopefully minimizing fear and frustration in the public and media in case of a vaccine safety scare event.	Formative research shapes the insights and training of vaccine providers, allowing them to prepare and address the concerns of young girls and their parents on this topic.
Absorptive	National immunization programme staff leading the process and conducting research allowed leadership, ownership and a genuine understanding of challenges related to HPV introduction and the need for concerted preparedness.	Formative research allowed the development of appropriate messages delivered through trusted channels and spokespersons to answer questions and concerns in case of a vaccine safety scare event.	Based on formative research, a specific module was included in the training on engaging with parents and responding to parental concerns. Together with a targeted questions and answers package, this aimed to strengthen vaccine provider capacities to respond to vaccine hesitancy and misperceptions.
Anticipatory	Formative research revealed more negative public opinion and misperceptions about the HPV vaccine and other information sources than anticipated. This allowed the programme to prepare key messages, questions and answers and a contingency plan to reach out to allies allowing them to respond to any crises at a faster pace than before.	Formative research revealed more negative public opinion and misperceptions about the HPV vaccine than anticipated. Based on this, messages were prepared to educate the public and the media regarding HPV vaccines.	Insights gained through research concerning perspectives on vaccines in general and HPV in particular from parents and girls were shared with providers, allowing them to anticipate and prepare for questions and concerns. This insight also allowed service providers to create a more appealing environment for vaccination that responded to the needs of beneficiaries.

Table 4.2. (contd)

Resilience	Programme Legislators, decision-makers, national and subnational managers	Population Parents, young girls, media, communities, opinion leaders	Service provision Vaccine providers, scientific community, research institutions
Transformative	Contingency plan with clear roles and responsibilities was developed based on insights gained through formative research. The formative process revealed knowledge gaps, misperceptions and capacity-building needs among service providers. As a result, training of vaccination providers was fundamentally changed. This is expected to have implications for future general immunization trainings of health workers as well.	A successful HPV vaccine introduction with transparent information, guidance and services that respond to the needs of beneficiaries may produce long-term positive impacts on population utilization of immunization services.	The training of health workers will allow vaccination providers to better respond to the needs of beneficiaries, not only for the HPV vaccine but also for vaccination in general. The value of the process was acknowledged at many levels, and the staff involved from the School of Public Health Management decided, in the future, to conduct more qualitative research to supplement the quantitative approach they traditionally apply to health research.

The impact on population level is difficult to show. It is not possible to know with 100% certainty if the public would have responded with more concerns and less resiliency to the HPV vaccine safety rumours that flourish on social media without the actions taken. The risk of a sudden drop in coverage, as has been seen in other countries, is also chronic. Nevertheless, at this stage, results are promising. For the initial period, 7 January–28 February 2018, 60% of 10-year-old girls were vaccinated with the first dose of the HPV vaccine, with some variation between subregions in the country. Even if there was an ambitious aim to vaccinate 89% of the targeted girls during this period of time, it is fair to say that the programme got a good start. The media has been positive, and the immunization programme has been diligent in responding with additional activities in subregions where coverage was low.

As for programmatic resilience, the process of using formative research to inform a new vaccine introduction was reviewed through an internal and informal exercise where national staff was interviewed by WHO staff and filled in questionnaires after the research process. This review showed that the process in itself built anticipatory resilience. It brought about a more realistic and clear picture of the target groups and significantly changed the team's assumptions about these. There was a much stronger than anticipated negative public opinion towards the HPV vaccine and vaccinations in general. The young girls who were supposed to receive the vaccine were very aware of rumours from other countries about extreme side effects. The process even found that doctors were unsure of the facts. It became evident that the trusted sources of information (for doctors and parents alike) were more likely to be hearsay from peers and the Internet. The sentiments of the national team following the research are illustrated by the following quotations.

> *What parents said was almost completely different from what we expected, both their knowledge of the benefits of vaccination and their sources of information about it.*

> *It was surprising to find huge gaps in knowledge among those representing public health. People are more controlled by rumors than public health guidance. Even among medical staff there was a huge gap of knowledge.*

The process is also likely to have strengthened the absorptive and transformative resilience of the programme as the communication plan clearly defined roles and responsibilities and established structures for contingencies. The fact that all planned activities outlined in the HPV introduction communication plan have so far been implemented is evidence of a resilient programme better prepared for this new vaccine than most before it. Another example of absorptive resilience is seen in a subdistrict that reported only 2% coverage a month after the vaccine introduction. The team lead responded to this need immediately by visiting the subdistrict and initiating increased communication, advocacy and further training for health workers.

The impact went beyond the Republic of Moldova. As part of the process, WHO developed a new tool, a field guide on formative research for new vaccine introduction (7). This field guide is intended for use by local staff with little or no experience with qualitative research. It provides simple, step-by-step guidance on conducting focus group or in-depth interviews. The guide will hopefully benefit many more countries introducing new vaccines in the future.

Lastly, the director and staff involved from the School of Public Health Management were enthusiastic about the process and outcome of the formative research. They decided, in the future, to conduct more qualitative research to supplement the quantitative approach they traditionally apply to health research.

Lessons learnt

Learning from the experiences of countries that have been struggling with acceptance of the HPV vaccine (or any new vaccine) is critical to ensure successful introductions of the HPV vaccine in countries that have yet to introduce it. This is especially important for countries that have less resilient health systems, more vulnerable populations and less capacity to respond to vaccine safety-related crises. Experience so far indicates that this was done with some important degrees of success in the Republic of Moldova.

The process shows that it is possible, with limited investment and in a relatively short time frame, to foster programmatic and population resilience through conducting rapid formative research which provides valuable insights to inform a new vaccine introduction. Supporting national immunization programme staff with no previous experience to conduct such research may not achieve the same academic-level results as external international consultants. Still, the capacity building, ownership and genuine insight into the challenges related to the new vaccine builds resilience that is all the more valuable, particularly when technical guidance and support from WHO throughout the process helps to ensure the quality of the research.

Based on encouraging results from the internal review of the process, WHO consequently revised the field guide into a tool for new vaccine introduction to help build resilience in more countries introducing new vaccines. The question remains whether a national team with no previous experience in conducting qualitative research could conduct such audience research entirely alone, based only on the field guide. Some training, mentoring and guidance from WHO may still be necessary to start the process, model the skills and develop initial capacity. More importantly, countries that have been successful in applying the tool should share their experience and resources with WHO and other countries to create a strong, sustainable and effective supportive environment for strengthening resilience in this domain.

This example describes actions taken in a situation where time and financial resources were limited. Within these limits, rapid research was possible with target groups that were considered representative of broad segments of parents, young girls and health workers. However, these groups are far from homogeneous in any society, and the next natural steps are targeted research with specific groups that prove to have low access to, low utilization of or lack of trust in the HPV vaccine (e.g. groups with certain socioeconomic or geographical characteristics or community affiliations). Such segmented approaches are necessary to reach the high coverage targets that ensure population immunity against vaccine-preventable diseases.

Acknowledgments

The authors would like to thank the people involved in this project: Ms Barbara A.K. Franklin, PhD, WHO consultant; Mr Alexei Ceban, Department of Vaccine Preventable Diseases, National Center for Public Health; Professor Oleg Lozan, Director, School of Public Health Management, Chișinău, Republic of Moldova; Professor Rodica Gramma, Associate Professor, School of Public Health Management and Director, Department International Relations and European Integration, State University of Medicine and Pharmacy "Nicolae Testemitanu"; Ms Valeria Chihai, Secretary, School of Public Health Management; Ms Ludmila Tihon, Master's degree student, School of Public Health Management; Ms Irina Batir, master's degree student, School of Public Health Management; and Ms Rodica Munteanu, Communication Officer, WHO Country Office, Republic of Moldova.

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Russian Federation. Strengthening system resilience through collaboration between WHO and a network of experts from centres of excellence

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Abstract

The WHO European Office for the Prevention and Control of Noncommunicable Diseases (NCD Office) was launched in 2014. The NCD Office, funded by a voluntary contribution from the Ministry of Health of the Russian Federation, established an in-country network of experts to provide technical support to Member States of the WHO European Region. This network is an example of building system resilience, usually defined as the capacity of a system to change and replace obsolete practices with innovative and more effective approaches. Strengthening system resilience in the health sector is essential to tackling the NCD crisis in Europe and achieving the Sustainable Development Goals (SDGs) (1). Since 2011, unprecedented political momentum has propelled world leaders to take action. A set of global and regional goals have been adopted that provide milestones for 2025 and 2030. However, the current policy commitment and response in many countries is proving to be inadequate to reach these goals. Strengthening system resilience is central to both Health 2020 and the SDGs. This inspirational example shows how such resilience can be built and describes an innovative WHO approach to support health development in countries.

Issue

Four types of NCDs – cardiovascular diseases, cancers, chronic respiratory diseases and diabetes – are the leading cause of death globally and are the target of concerted global action (2). Premature mortality from NCDs constitutes one of the major challenges for development in the 21st century and must be addressed with proven and innovative policies and strategies if the SDGs are to be reached. SDG target 3.4 on NCDs aims to "By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being" (1).

One of the four priority areas of Health 2020, the WHO European health policy framework, is to create resilient communities and supportive environments (3). Specifically, it recommends linking with new and evolving types of partnerships for health, active at various levels of government across the Region.

A complex array of regional and global forces can challenge people's health and determinants. In isolation, no country can resolve the challenges to health and well-being. Partnerships are needed to harness innovation and scale up effective policies and strategies. In an increasingly interdependent world, the need for countries to act together becomes more critical. The resilience of systems must be strengthened if both Health 2020 and the SDGs are to be achieved. In order to address the challenge of NCDs, the resilience of national-level systems must be strengthened to ensure countries are able to adapt and effectively manage the increasing and evolving NCD crisis.

Action

After the launch of the WHO NCD Office in Moscow in 2014, a network of experts was established to draw on the expertise in the country and provide more effective and sustainable technical support to other countries in the Region. The network also aimed to facilitate the sharing of knowledge and expertise between countries, develop partnerships between policy-makers and health professionals and improve health outcomes in the Region.


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Russian and international experts attend the network's launch in 2016.

Policy-makers are required to apply a large body of knowledge and expertise on the prevention and control of diseases such as cardiovascular diseases, cancer, chronic respiratory diseases and diabetes. These conditions threaten health, livelihoods and lives. Since 2014, more than 40 Russian experts from leading scientific institutions in the Russian Federation have joined the NCD Office team in a wide range of activities, including country visits, and multicountry meetings, conferences and workshops. These scientific institutions are regarded as leaders in their field in the Russian Federation; they all conduct fundamental and applied research and provide scientific, academic and medical training while providing treatment.

These experts provide a pool of experience, knowledge and skills across a wide range of subjects. Their fields of expertise range from strategic policy-making within public health, epidemiology, research and surveillance, to prevention of NCD risk factors and treatment of specific NCDs. Working closely with professionals and policy-makers in each country, their familiarity with similar health systems, combined with a common language, creates an efficient partnership that gets results.

Each visit or activity is carefully planned with the NCD Office and targeted to meet a country's particular needs. Experts may contribute to analyses, assessments, surveys, strategies, capacity building and bridge building across sectors. They assist with training, strategizing and planning, facilitating the collection of evidence-based data and sharing of good practice. The discussions stimulated by country visits were described as enriching experiences on both sides.

The approach of the NCD Office is an innovative way to provide long-lasting and sustainable support to policy-makers and health professionals in countries. This innovative system of collaboration between the Regional Office and the Russian Federation has improved the effectiveness and resilience of WHO technical support to Member States.

Impact

This approach has enabled WHO to harness the technical expertise of the Russian Federation and create partnerships between institutions throughout Europe. It is an example of strengthening system resilience on two distinct levels: transforming the way that the Regional Office provides technical support to countries and strengthening the adaptive, absorptive and transformative capacity of individual health systems.

Achieving the SDGs requires a proactive approach to resilience, often referred to as the transformative capacity of a system. This innovative approach has transformed the way in which WHO provides technical support to countries in the Region so that systems are more resilient and better able to respond and adapt to external shocks. Previously, countries were supported mostly by international experts based at the Regional Office (Copenhagen, Denmark) or at WHO headquarters (Geneva, Switzerland). Providing much needed technical support to countries in the Region was more dependent on the availability of both financial and human resources with the necessary technical expertise and in-depth local knowledge of eastern European and central Asian health systems and cultures. The availability of both varies, and the ability of WHO to provide support to these countries and build capacity in the Region was limited. WHO now has access to a range of experts based in the Russian Federation, increasing the resilience of WHO technical support to countries dealing with external shocks such as limited resources or unexpected health policy challenges.

This collaboration and joint activities between the WHO NCD Office and the Russian Federation is strengthening the resilience and building the adaptive and absorptive capacity of health systems in the Region. This has increased the effectiveness of national health systems to respond to the ongoing challenge of preventing and controlling NCDs.

One area of joint collaboration between WHO and experts from the Russian Federation is through joint capacity-building activities in countries throughout the Region. Capacity building among professionals responsible for combatting NCDs provides inspiration and equips them with knowledge of current best practice and how to overcome barriers. For example, Russian experts from various institutions contributed to the development and delivery of training courses held in Moscow on the prevention and control of NCDs. These were conducted in Russian at regional and subregional levels and were attended by countries across eastern Europe and central Asia. These capacity-building activities have also forged ongoing professional relationships between policy-makers and health professionals in different countries. Following these activities, knowledge sharing and collaboration continues, and the capacity building that has taken place increases the sustainability and effectiveness of activities to prevent and control NCDs throughout the Region.

A specific example of this was a joint initiative to train-the-trainers on reducing harmful alcohol consumption. Through the network, WHO and the Russian Federation were able to build capacity in the Region for reducing harmful alcohol consumption – a major issue in eastern Europe and central Asia and one of the key modifiable risk factors for NCDs. WHO collaborated with Russian experts to develop, adapt and pilot a train-the-trainer toolkit to support Member States to implement screening and brief intervention programmes in primary health care settings. A training session was developed in collaboration with Russian institutions and attended by participants from around the Region. These participants now use their new skill sets and the toolkit to train practitioners within their national primary health care system to deliver screening and brief interventions to reduce harmful alcohol consumption.


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Since 2016, Russian experts help to develop and implement training courses on the harmful use of alcohol.

Another way in which the network has helped strengthen the resilience of individual health systems is through joint activities to carry out health system assessments. The objective of a health system assessment is to produce pragmatic policy recommendations on how a national health system can be strengthened to accelerate action on NCDs. A system assessment also synthesizes knowledge and experience across the Region on what works and identifies barriers. Russian experts participated in multidisciplinary teams comprised of both national and international experts. Activities focused on the level of implementation of population-based interventions and related barriers in Armenia, Kazakhstan and Serbia. These country studies contributed to a regional synthesis study and have informed policy recommendations at the national and regional levels.

The network has also been utilized to improve surveillance of NCDs in the Region. Reliable and up-to-date surveillance provides the evidence base for effective policy-making and enhances the transformative capacity of health systems. Russian experts have participated in a project to establish indicators and an information system to monitor progress on NCDs in Turkmenistan. In addition, the WHO STEPwise Survey of NCD risk factors (STEPS) is a key WHO initiative that provides vital information to policy-makers in low-resource settings (4). WHO has collaborated with Russian experts to organize and deliver STEPS survey training sessions in Armenia, Belarus, Georgia and Tajikistan. These surveillance initiatives provide the essential information to transform health system structures and means of operating so that they are better able to respond to the evolving NCD crisis.

Lessons learnt

There are considerable benefits to involving Russian experts and institutions in the work of the NCD Office. Russian experts have a deep knowledge of the context in which the countries of eastern Europe and central Asia work. Their health systems, which share a similar history, have diverged over the last 20 years. Understanding the structure, ways of working, causes of existing problems and the general culture enables Russian experts to provide more targeted recommendations. This in turn strengthens WHO’s technical support in this part of the Region and enhances the resilience of this system of cooperation. As such, the system is better able to adapt to potential changes and cultural challenges that would be more difficult to overcome without the network.

Participants take part in STEPS training for data collectors in Belarus.

Sharing a common language is key to enabling effective communication and exchange. Many policy-makers and health care practitioners from eastern European and central Asian countries speak Russian rather than English. With no language barrier, the experts are able to listen and communicate more directly and effectively. Given their past, they can not only identify and share good practices from the Russian Federation that may be applicable in eastern European and central Asian countries, but also recommend the best way to apply international practices to these specific contexts. They are also better able to establish long lasting and more sustainable partnerships.

Through their involvement in international teams, the experts learn from each other and gain valuable experience and knowledge. Working side by side on country visits, they have opportunities for face-to-face interactions and discussions on a valuable professional footing. While preparing to participate in visits or developing materials for training courses, they increase their familiarity with WHO and other international recommendations, guidelines and materials.

Russian experts can apply the experience they have gained within national working groups of international health projects, including WHO projects such as the development of national NCD strategies and the STEPS survey. Many are leading specialists in the Russian Ministry of Health and have direct influence on policy-makers in the country. They are able to share their expertise and knowledge with colleagues who represent regional or national institutions and whom they meet at meetings and conferences. For some experts, participation in WHO country work is their first opportunity to work at national or international level.

The barriers encountered while establishing the network can provide valuable lessons for starting similar initiatives. A high level of competition often exists between academic institutions, and they may not be accustomed to working together. In the initial stages, asking these institutions to collaborate for the first time may produce difficulties. In addition, expanding the network to other regions of the Russian Federation has been difficult as most of the experts are based at institutions in Moscow. This may be difficult to overcome, as academic institutions are often based in major cities, and geographically dispersed institutions may find working together on a regular basis difficult. Further, the language barrier has hindered and limited network expansion outside of Russian-speaking countries.

However, this collaboration is a long-term investment. Knowledge flows from one generation to the next; most of the experts also teach and can transfer the knowledge they have acquired to their students. For example, in the Higher School of Health Administration of the I.M. Sechenov First Moscow State Medical University, the content of courses that are under development within the NCD Office and conducted in the Russian Federation are already being included in the curriculum of undergraduate and postgraduate health care studies. The Higher School recently started a two-year master's programme for non-health care professionals on the prevention and control of NCDs, directed towards policy-makers from municipal governments. Strategic guidelines and recommendations from WHO and the NCD Office training materials provided the basis for this course.

The Russian experts report to the NCD Office that they are pleased with the direct relationships they are developing with eastern European and central Asian countries – relationships that will benefit future work and collaboration and the ability of health systems to tackle the NCD crisis.

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The former Yugoslav Republic of Macedonia. Building resilience to cope with heat waves

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Abstract

High ambient temperatures have a significant impact on society and population health, including a rise in morbidity and mortality. Episodes of heat lasting for several days are often referred to as heat waves and can be associated with tens of thousands of premature deaths. In the former Yugoslav Republic of Macedonia, the most striking weather anomaly was in 2007, when the national government declared a nationwide heat-wave emergency. The content of this inspirational example outlines a wide range of coordinated actions at community and system levels to adapt, anticipate and manage the many problems caused by heat waves. The example shows the need for intersectional action to build adaptive, absorptive, anticipatory and transformative resilience capacity in both communities and institutions in order to effectively counter the harmful health effects of heat waves.

Issue

During the summer of 2007, daily temperatures reached 43°C and caused more than 1000 excess deaths at national level (compared to the averages of 1994–2008). In Skopje, the capital city with around 600 000 inhabitants, temperatures in July 2007 were 3.4°C above the monthly average, and deaths were 16.5% higher than the average between 1994 and 2008. The direct health effects of heat waves could become a significant problem, especially with more than 60% of the population living in cities and urbanization increasing.

The heat cut-off point for the maximum temperature for Skopje was 30.8°C. Under heat-wave conditions, an increase of 1 °C above the heat cut-off point for Skopje increased total mortality by 4.8%. Increased mortality during heat waves is higher among older people with chronic diseases, and cardiovascular and respiratory diseases (1). Compared to the baseline period (1986–2005), heat-related mortality in Skopje is projected to more than double in 2026–2045, and more than quadruple in 2081–2100 (2).

It has been estimated that the expected impact in the country will be much larger than if temperatures remain at the observed historical levels. During the period 2071–2099, an overall excess of 305 and 871 attributable deaths per year is expected under the Representative Concentration Pathway (RCP) 4.5 and RCP 8.5 scenarios respectively, in addition to the 14 attributable deaths estimated under the historical scenario (3). Under anticipated future warming conditions, the length, frequency and intensity of heat waves are expected to increase. Taking into consideration that the national population is aging, an increase in heat-attributable deaths is a serious risk. In order to avoid such negative scenarios, effective adaptation measures must be taken. Policies and plans for heat mitigation and adaptation are urgently needed in European countries in order to prevent the expected increase of heat-related deaths in the coming decades (4).

Protecting people from health hazards and unexpected health damaging events and shocks is a key domain and remit for public health. This is critical, particularly for vulnerable populations that are often the first victims of such unexpected shocks. The impact of climate change, including heat-wave events, requires strengthening all four main capacities of resilience mentioned in the introduction of this Compendium. Indeed, strengthening the adaptive, absorptive, anticipatory and transformative resilience capacity in both communities and institutions is needed.

Action

A national heat–health action plan was developed within the country's strategy to adapt the health sector to prevent health consequences associated with extreme heat due to climate change (5,6). Its goal is to reduce morbidity connected with heat waves by issuing heat and health warnings, encouraging planning in the relevant sectors, prioritizing health in all policies, raising public and health sector workers' awareness and mobilizing resources for managing heat effects.

A national framework was established to build adaptive capacity for climate change resilience in the public health community – to better address the effects of climate change – and to oversee activities. This included a national, multisectoral steering committee and a technical working group, which defined the scope of the national adaptation plan, methods, peer review process and process for defining priorities using a WHO comprehensive framework for developing national climate change health adaptation strategies (7). The WHO framework incorporates an assessment of climate change impacts, a vulnerability assessment, the modelling of projected health impacts, an evidence-based evaluation of intervention options, a strategy for implementing interventions and systematic evaluation of all activities in an iterative manner.

A team from the Institute for Public Health, under the direction of the national steering committee, conducted a scoping exercise to identify readily available information and data on the heat-associated health exposures and risks to population health, and vulnerability and impact assessments. A variety of qualitative and quantitative methodologies were used in the assessment: literature reviews, interviews, focus groups, time series and regression analysis, damage and adaptation cost estimation, and scenario-based assessment.

Several workshops were held during 2009–2010 supported by the WHO Regional Office from Europe, to identify general priorities and provide strategic direction for the development of a national heat–health action plan, using WHO's guidelines (8). Representatives of the Ministry of Health, the Institute for Public Health, the Ministry of Environment and Physical Planning, the Hydrometeorological Institute, the Crisis Management Centre, the Directorate for Protection and Rescue, emergency medical services, public health centres, the Institute of Occupational Medicine, WHO, the Macedonian Red Cross, the media and civil society attended the workshops. Broad stakeholder engagement and a participatory approach towards adaptive management result in and support more interdisciplinary implementation efforts. Key factors considered at the workshops included:

- the size and the nature of the climate change problem related to health
- effective interventions
- the goal and objectives of the strategy for each of the stakeholder-defined priorities
- involvement of institutions and responsibilities

- indicators
- financial implications of each proposed intervention.

To develop the health adaptation plan, three multisectoral working groups were established, with specific responsibilities for assigned priority areas: air quality, extreme weather (heat and cold) and infectious diseases.

According to the national health adaptation climate change strategy, the health care system in the country has an important role in establishing adaptation, and health prevention and response measures to address the health risks related to climate change such as (6):

- strengthening the resilience of existing public health capacities for early detection and adequate response;
- anticipating the consequences of emerging diseases possibly related to climate change;
- raising awareness among the population about the possible links between climate change and health;
- implementing crises and disaster health management systems and plans; and
- establishing early warning systems.

Other areas addressed by the national health adaptation strategy include: adapting the health care infrastructure (hospitals, nursing homes) to be more resilient to the effects of heat, fires and floods; developing local "Safety Hospital" plans to cope with disasters; and increasing awareness of how people can adapt to changes in climate. Developing the strategy publicized the need for greater emphasis to be placed on climate change and its impacts; the need for governments to focus on this problem; and measures individuals can take to mitigate the effects of climate change on their health.

In order to increase the resilience of the health sector to cope with the health impacts of climate change and to strengthen national capacity for assessing these impacts, the following activities took place:

- the training of more than 300 health and environmental professionals, journalists and other profiles on the health effects of climate change, with an emphasis on heat waves;
- an assessment of the health effects of climate change in the country;
- a study that examined the impact of heat waves on morbidity in summer months in the country for the period 1994–2009;
- a study on the correlation between the occurrence of Salmonella infection and average weekly temperature distribution for the period 1996–2009;
- a study on the presence of the vector *Aedes albopictus* in the country, published in 2011;
- a study on the impact of climate change on pollen micro flora related to the respiratory allergies among the adult population in Skopje, published in 2011; and
- a publication on the effects on health of climate change in the former Yugoslav Republic of Macedonia, available in English and local languages.

Climate change mitigation efforts by the health sector include implementation of activities on energy efficiency and promotion of the use of renewable energy sources in hospitals and health institutions. Such measures were initiated by the Ministry of Health with WHO support in 2009 in two pilot municipal hospitals in Gostivar and Shtip. Furthermore, the Government adopted measures for refurbishment of all hospital facilities at secondary and tertiary levels in the country, including energy efficiency measures. These measures help to reduce greenhouse gas emissions at municipal level and raise awareness of health managers and staff on the effects of climate change. Hospital staff training is expected for energy saving and environmental protection strategies.

One of the main proposed solutions is the implementation of a structured system for timely heat-wave announcements (alert system), particularly during the period of 1 May–30 September (5). This includes: the set-up of a responsible body, a 24–48 hour early heat warning, specific thresholds for action, and priorities for vulnerable populations, workers' health and communication. The alert system is part of the broader approach designed by the national heat–health action plan. Further elements are:

- coordination body for plan implementation;
- communication plan to inform the public and the health and social sectors about protection during heat waves, and the recommendations given by the Ministry of Health, as addressed to health workers, the general population and at-risk groups;
- recommendations and (medium-term and short-term) strategies for reducing exposure to heat inside health and social institutions, and special protection plans for vulnerable population groups; and
- long-term planning for preparedness of the health and social care systems, including: planning and training of personnel, appropriate health protection, creating green areas, improving the energy efficiency of hospitals and reducing the emission of greenhouse gases.

Regarding implementation, monitoring and evaluation of the plan, certain activities took place. First, a heat–health watch system operates during the summer months, with advice from the National Institute for Public Health and the Ministry of Health, with four levels of response and appropriate advice. The heat–health action plan provides a summary of key measures to be undertaken by the responsible sectors and institutions. These measures aim to decrease morbidity connected with heat waves by issuing heat and health warnings from the Hydrometeorological Institute to encourage planning in the relevant sectors and to raise public and health worker awareness, as well as to mobilize the resources for managing the heat effects. The action plan consists of a set of previously agreed upon activities and preparations to be carried out by the health sector and institutions, in order to raise awareness and reduce heat risks. Furthermore, the plan gives guidance for the responsibilities of the institutions and individuals taking measures after a heat-wave announcement.

Second, information leaflets for protection against heat waves, aimed at the general population, managers in health and social institutions, general practitioners and workers were developed and printed. The Red Cross, regional public health institutes and their local branches, municipalities and the Labour Inspectorate distributed the information.

Third, an app for Android mobile phones providing heat and health warnings and related recommendations was also developed.

The Government endorsed the heat–health action plan in February 2012, and it is now fully established, following the successful piloting of specific heat-protection actions in the summers of 2010 and 2011 (7).

Representatives of the Macedonian Red Cross distribute information during the heatwave in Skopje.

Impact

While there have been specific project benefits, such as increasing the awareness among health professionals of the health impacts of climate change, and the development of the heat–health action plan and the cold health action plan, the broader benefit has been the increased engagement of key stakeholders and policy-makers with this agenda (8). Before the process was initiated, climate change and health topics were largely marginalized, with activity happening in silos. Creating such cooperative and supportive environments is crucial for strengthening resilience as recommended by Health 2020 and its priority area four (9).

In the current implementation period, this collaborative approach has proven to work well. The heat–health action plan was evaluated in 2015, and 100% of survey participants from all implementing institutions (N=38) agreed that proposed activities and approaches were appropriate. At the time of the evaluation, more than half of the proposed activities were implemented (52%); lack of staff and funding, as well as staff indifference, accounted for the other half. Of the respondents, 83% called for more field visits, targeted and tailored action for groups and capacity building at local level: general practitioners, social care workers, employers, inspectors etc. Most respondents (96%) would like the heat–health action plan to continue but with more funding from the central budget. Many of the successes in the country's climate change health assessment have already begun to have an impact. Nevertheless, building adaptive and anticipatory resilience capacity remains an ongoing concern. Throughout the process, a number of tools were utilized which allowed practitioners to organize information on the hazards and at-risk populations in order to prioritize responses. These successes provide an ongoing foundation for future collaboration and activity.

The study in Skopje calculated the projected average annual mortality attributable to heat in the absence of adaptation or acclimatization during specific time windows, and evaluated the contribution of each source of uncertainty on the final impact (2). Improvements in infrastructures and health care services together with heat-adaptation measures have beneficial effects on reducing the impact of heat on mortality. It can be accomplished by reducing heat-wave-related morbidity and mortality through heat–health warnings, especially for the most vulnerable groups: older people, infants and children up to five years old, the chronically ill, people who are overweight, people who work outdoors, and those whose social factors (nationality, profession, educational level etc.) make them particularly vulnerable.

In order to strengthen preparedness for crisis situations and climate change-related emergencies, a simulation exercise took place on 22 May 2013, in the Strumica Region in the country. The key stakeholders were the Ministry of Health, Strumica General Hospital (an important regional hospital centre), emergency medical services, the Crisis Management Centre, the Red Cross, fire rescue units, the Ministry of the Interior, the Ministry of Defence and WHO. Prior to the simulation exercise, preparatory meetings were held to establish the parameters of the exercise such as the number of expected casualties, trigger indicators for activating the emergency response plan, triage and patient traffic flow, as well as the responsibilities of hospital and emergency medical staff. The simulation allowed the authorities to test general preparedness and also the implementation of the national heat–health action plan (10).

Firefighters evacuate the injured in a simulation exercise in Strumica Region on 22 May 2013.

The former Yugoslav Republic of Macedonia took part in a three-year (2009–2011) WHO project "Protecting health from climate change", a seven-country initiative, funded by the International Climate Initiative of the German Federal Ministry for the Environment, Nature Conservation and Nuclear Safety. The overall goal of the project was to strengthen capacity in understanding and responding to the health risks of climate change, as well as to develop the heat–health action plan. Within this project, a cost–benefit analysis showed that it is possible to compare cost damages incurred by disease and deaths due to heat waves and climate change to the costs of adaptation.

Moreover a partial reduction in health impacts is an expected benefit as a result of adaptation measures implemented (in this case a heat–health action plan). Investment costs such as infrastructure, equipment and training are important for effective health preparedness and response. In the country, the main one-off investment is made by the Ministry of Health, and social infrastructure and lesser investments are made by local governments. These costs include energy efficiency measures, air-conditioning and water fountains in hospitals and nursing homes, and communication and awareness-raising for medical staff and the general public. The total cost of health damage attributed to climate change and heat for the selected outcomes in the country was estimated at 170 million local currency units (LCU) per year. A cost–benefit analysis compared the damage costs of the increase in disease cases and of deaths not averted with the costs of adaptation and its expected reduction of negative health effects. The adaptation cost is estimated to be 12 million LCU. When compared with the total damage costs (170 million LCU per year), the adaptation costs appear to be relatively small (11).

Lessons learnt

In order to ensure effective implementation of planned actions and impact, organizational arrangements are crucial. The Ministry of Health has overall responsibility for implementing the heat–health action plan. Within the Ministry of Health, the Climate Change and Health Commission was established in June 2009. The Commission has participated in the preparation of the national heat–health action plan, and it cooperates in the execution, surveillance and evaluation of the plan. The Commission is responsible for coordinating the involvement of institutions during the implementation of the plan's activities, as well as for promoting multisectoral cooperation. One recommendation is that, when necessary, people from other relevant institutions should be included in the Commission and in the plan implementation such as: the Institute for Public Health and public health centres, the Institute of Occupational Medicine (WHO Collaborating Centre for Occupational Health), the Crisis Management Centre, the Hydrometeorological Institute, the Directorate for Protection and Rescue, departments that improve the living environment within municipalities (in the first phase, active participation of the city of Skopje), the Ministry of Transport and Communications, the Ministry of Labour and Social Policy, the Ministry of Education and Science, the Macedonian Red Cross, the media and the non-governmental sector. All these effects can be seen as actions fostering supportive environments for resilience and health.

Lessons learnt during the process 2011–2015 are summarized as follows.

- Information on climate change impacts needs to be translated from the scientific research domain into language and time scales relevant for policy-makers.
- The need for national data is crucial, as is the recognition of limited human capacity.
- All relevant stakeholders need to be involved, but their informational needs may vary.
- More broadly, strengthening health security would require:
    - maximizing synergies with existing instruments, including the heat–health action plan;
    - preparing health and social care sector workforces to respond to health-related consequences of climate change and strengthening of health services to address climate-related events in a timely manner;
    - promoting consideration of the health issues and related responses within other sectors; and
    - building capacity in the health and social care sector workforce.

Community awareness and engagement are key. Intensifying the dissemination of information through workshops, roundtables, preparation of brochures, leaflets, campaigns, the use of electronic and print media, social networks, etc., should be basic tools to increase community awareness of the problem of heat waves, other extreme weather events and climate change.

Using preventive interventions and policies to reduce the health risks and the potential effects of climate change and extreme weather events on population health requires further capacity building in the health sector. This is especially relevant in the field of environmental health. Capacity should be strengthened in order to better provide, recognize, assess and control the changes in the environment and the related hazards. Furthermore, increased focus on modelling and adaptive management and effective use of local community resources and assets is needed to strengthen the resilience of the community as part of building an integrated, efficient and effective public health approach.

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United Kingdom (England). Supporting local systems to tackle the social determinants of health inequalities

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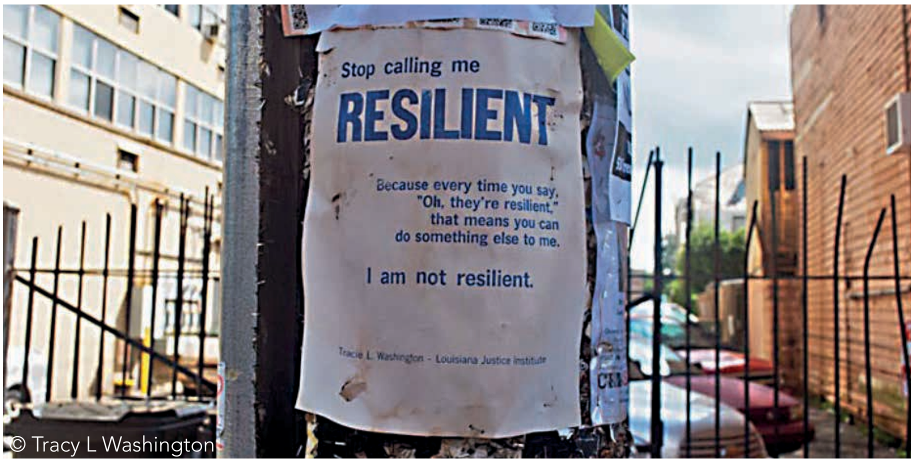
Abstract

Developing system approaches to resilience is not an easy option. The Neighbourhood Resilience Programme (NRP) described in this inspirational example from the northwest of England highlights some of the main challenges and opportunities for such an innovative approach. As the authors conclude, such an approach demands time, energy, commitment and imagination from all involved. The example throws light on the possibility to move beyond traditional, individual, topic-based approaches to collaborative partnerships with residents, local workers and institutions. It addresses major issues and works on key social, environmental, cultural and economic elements that characterize local neighbourhood systems that impact on resilience, health and well-being. The on-the-ground work of the authors and their partners at community level maintains that strengthening resilience that impacts on health and the reduction of health inequities requires such a system perspective. Although in its early phase of development, several powerful lessons can be drawn from NRP and its system perspective. Such lessons are useful for action that aims to strengthen resilience to promote health and well-being and to address social and economic determinants of inequalities. These lessons are essential for developing resilient neighbourhood systems.

Issue

There is a growing need to focus on a systems resilience approach. The concept of resilience is typically presented as a property of individuals, communities, organizations or policy systems like the health system (1,2). More specifically, resilience is understood to be the "capacity *to endure, adapt and generate new ways of thinking and functioning*" in the context of change, uncertainty or adversity (3). As evidence of the negative impacts of global recession on social and health inequalities accumulates, health policy attention has turned to the question of how the resilience of communities bearing the brunt of these inequalities can be enhanced (4). The other case studies in this WHO Compendium reveal the extraordinary resilience and creativity of diverse communities around Europe. However, people bearing the brunt of social injustice may resist resilience initiatives if, as the poster below illustrates, they experience them as a call to "Do It Yourself".

Many health professionals understand that the ability of people and communities to bounce back from adversity – their so-called adaptive capacities – is depleted by upstream social, economic, commercial and political drivers of inequality, over which they have little or no control (5). Health professionals know there is a risk that resilience initiatives can increase the existing burden of responsibility already felt in disadvantaged communities (2). Many also understand that enhancing adaptive capacities in communities requires those working in the public, private and third (nongovernment) sectors, and the organizations that employ them, to operate differently, to forge more equal, inclusive and socially responsible relationships with local communities.



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Street poster "Stop calling me RESILIENT".

But the term community resilience, and the language that surrounds it, may (if not correctly understood) send out ambiguous messages. The community is clearly identified as the target for action. Professionals are assumed to have an important supporting role, but they are told they must avoid creating dependency: be ready to withdraw as the community gains in confidence. An alternative approach is to understand resilience as an emergent property of systems defined in terms of a particular geography e.g. a neighbourhood. This shifts attention from individuals or communities of place or interest, to "action to enhance the personal and collective capacity of *people and institutions* to respond to and influence the course of social, economic and environmental change" (6). From this perspective, maximizing resilience requires the release of the adaptive capacities of all the actors, institutions, objects and processes interacting within a neighbourhood system. This means that place-based resilience initiatives should have a dual aim. First is to release the capabilities of local people to participate in decision-making spaces and act for change. Second is to release the capabilities of local workers and institutions to remain in a neighbourhood and operate in ways that recognize community members as *equal* partners in responding to existing and future challenges.

Action

NRP is a system resilience initiative by the Collaboration for Leadership in Applied Health Research and Care in the North West Coast area of England (CLAHRC NWC) (7). It is funded by the National Institute for Health Research and CLAHRC NWC partners. NRP operates in nine "Neighbourhoods for Learning" selected by local authority partners[28] as ward-sized[29] areas experiencing social and health disadvantage. The aim is to tilt the inequalities see-saw (Fig. 4.1) by:

- changing local power dynamics to give residents greater control over decisions and actions impacting on their lives; and
- supporting actors in the system to work together to design, implement and evaluate local initiatives aimed at enhancing system resilience.

No new investment is needed; instead existing services/activities are improved and/or

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[28] Lancashire County Council, Cumbria County Council, Blackpool Borough Council, Blackburn with Darwen Borough Council, Halton Borough Council, Knowsley Borough Council, Sefton Borough Council, Liverpool City Council and Cheshire West and Chester Council.

[29] Electoral wards are the geography used to elect local councillors in the United Kingdom.

redesigned, informed by diverse evidence. The primary focus is on up-steam determinants of health inequalities at a neighbourhood level. Drivers of inequalities operating at city, regional and national levels are not excluded. Key steps in the Programme are briefly described below followed by examples of work in two neighbourhoods.

Fig. 4.1. Tilting the inequalities see-saw

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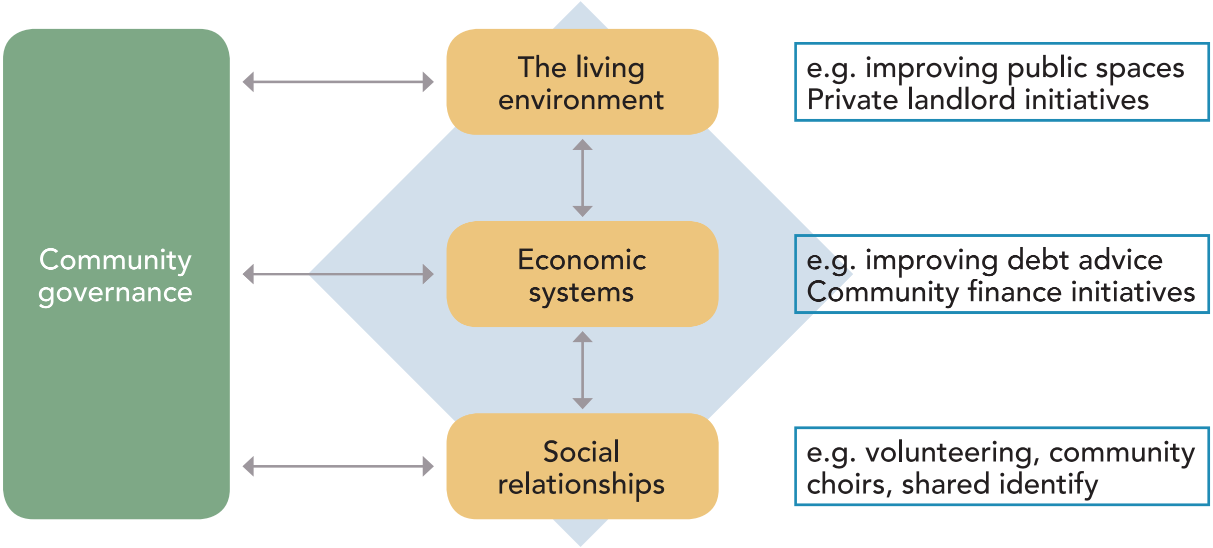
Forging alliances and brokering knowledge among local partners

A review of resilience-related activities/policies currently undertaken by local councils across the United Kingdom informed the development of the Neighbourhood Resilience Framework (Fig. 4.2).

Fig. 4.2. The Neighbourhood Resilience Framework



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The Framework comprises four domains:

- the living environment (e.g. community gardens);
- economic systems (e.g. promoting uptake of living wage by local businesses, community finance initiatives);
- social relationships (e.g. volunteering schemes and social clubs); and
- community governance (e.g. participatory budgeting schemes, tenant associations).

Profiles of existing resilient-related activities, resources and services across these four domains already in place in each neighbourhood were produced.

The Household Health Survey was conducted in each neighbourhood in 2015 and will be repeated in 2018. This provided data on mental and physical health and well-being and on the economic, environmental, social and governance components of neighbourhood resilience. Routine data collected by partner organizations are also being collated including, for example, data on debt levels and housing conditions. Resident-led inquiries are crucial to the Programme. They tap into the experiential knowledge of those who live and work in the neighbourhoods to inform the redesign of existing activities. These different information sources are being incorporated into online interactive data resources for each neighbourhood and have informed decisions about the focus of action. They will also allow changes in neighbourhoods to be tracked over time.

Bringing all system stakeholders together and designing and delivering local programmes

Strategic management of the Programme across the nine neighbourhoods is the responsibility of a management group that includes representatives of local authorities and university partners. In each neighbourhood a local oversight group was established. This group has responsibility for designing and implementing local action. Membership of local oversight groups includes residents, staff from the local council, and third sector organizations. Members of a central academic team coordinate the work in each neighbourhood. This role includes facilitating connections between different groups with a stake in the neighbourhood system, brokering the different knowledge they bring to discussions, helping deliver local activities and collecting data for the process evaluation.

The Community Research and Engagement Network (COREN) was established to support the development of power within the local communities, increasing their confidence in their ability to contribute as equals in the Programme. Third sector organizations are funded to employ a COREN facilitator in each neighbourhood. COREN facilitators are often local residents, and their main role is to recruit and support local people to get involved in the Programme as resident advisers. These advisers are paid a fee for their contribution, and their role is to engage other residents in the work and to undertake local enquiries to inform and evaluate the Programme.

Local work began with an open meeting in each neighbourhood attended by residents, staff of local authorities, the COREN facilitator and a range of others from the public, voluntary and private sectors. Results from the Household Health Survey and the profile of existing resilience-related activities in the area were presented to stimulate discussion about challenges in the neighbourhood. Further open meetings followed, and slowly a consensus emerged about the broad focus for action. Table 4.3 illustrates the range of topics chosen in the neighbourhoods. Following these open meetings, small groups were formed to develop specific activities around the selected topics. These activities have included resident-led enquiries focusing, for example, on availability of local debt advice services and patterns of use of local community assets.

Table 4.3. Focus for action in the neighbourhoods

Neighbourhood	Topics
Blackpool	Improving the quality of privately rented accommodations and supporting tenants – working with LA housing teams and transience programme
Liverpool	Rethinking the role of the high street and taking action on air pollution – inputting to Mayor's citywide air pollution strategy
Knowsley	Promoting community cohesion and environmental quality working with third sector housing provider and developing links with LA housing team
Cumbria	Focusing on increasing employment for local people and enhancing work-related skills
Preston	Improving relationships between diverse communities in the neighbourhood and improving the environment
Rossendale	Increasing social cohesion and reducing social isolation
Cheshire West and Chester	Improving the quality of public spaces and increasing safety especially around schools
Blackburn with Darwen	Improving the acceptability and accessibility of community resources and environmental quality
Sefton	Reducing indebtedness – improving access to high-quality debt advice and support, working with schools and young people

Source: reproduced with permission from CLAHRC NWC.

A critical question in the process described in this narrative is: what will success look like? From a systems perspective, impacts will not be linear; there will be unanticipated (positive or negative) impacts, and small changes may have large impacts on the system. Given the diversity of activities, indicators of success are expected to vary across neighbourhoods. These may range from improvements in environmental quality, reduced air pollution, increased road safety and more assertive action to improvements in the quality of privately rented accommodation and reduced social isolation. However, more time is needed to assess whether such improvements are achieved and even longer before they are translated into tangible health outcomes. Resilient systems are well connected systems with easy flows of diverse sources of information. Therefore, resilience will have been enhanced if increased social connectedness can be demonstrated within these neighbourhoods. This would include more and new networks across disparate groups of residents, more extensive, trusting relationships between residents and agencies working in the neighbourhoods and more constructive relationships between these agencies themselves.

Impact

Selected examples from the NRP in Liverpool and Sefton were chosen to give an idea of the Programme's impact.

Old Swan, Liverpool: "A destination to come to rather than going through"

The quotation above captures the aspiration for the Programme expressed by a member of the Local Oversight Group in the Liverpool neighbourhood, which has named itself Better Old Swan (BOS). BOS comprises residents, the COREN organization (Liverpool community and voluntary services), local businesses and others working in the area, including elected councillors, local authority staff and third sector organizations. BOS organized consultations with a wide range of local stakeholders to identify topics for actions. Over time, interest coalesced around the local economy and, in particular, regeneration of the local high street, increased employment and improvements in the environment.

The local economy in Old Swan faces multiple challenges which resemble those faced by high streets and town centres across England (9). Rates of unemployment and household poverty are higher than the national average (10). The high street is unattractive. Residents feel there are too many charity shops, betting shops and empty properties, and a lack of places to eat with few cultural activities. The area is divided by major roads resulting in traffic jams, noise, increased risk of road accidents and hot spots for air pollution (11). The large shops opened on the boundaries of the ward are also a threat to the already weakened high street.

Faced with a broad consensus about the problems, BOS convened a group of local residents and professionals to drive the work forward. Currently, they are undertaking activities to help decide which local actions would work best to bring about change. These activities include a rapid review of different types of evidence on what has worked to enhance local economies in Liverpool and other cities; an audit of activities and patterns of use on the high street; and hosting meetings with academics evaluating resident-led improvement initiatives in other areas.

We are inviting local residents to take photographs of Old Swan, good & bad, old & new, and everything in between. Include streets, buildings, parks and places which are significant to you.

We would also like to see any historical images which capture the essence of Old Swan.

All photographs will be used to create a living exhibition and become part of a research project to Better Old Swan.

BOS leaflet by Mark Simpkin in Old Swan, England, United Kingdom.

Four areas for action have been identified, and initiatives in each are at different stages of implementation. Early insights from the process evaluation suggest that BOS is having positive impacts – some direct and some serendipitous spin-offs – across the four domains of the Neighbourhood Resilience Framework.

1. Improve economic resilience.

Two resident advisers launched a community magazine to give organizations from all sectors an opportunity to promote their services to local people. It will be published in spring 2018 with a print run of 8000 copies and a potential readership of 20 000.

The Business Breakfast Club was set up to create a space for high street business owners to network, share knowledge, identify areas for improvement and build partnerships with others to increase access to training and resources. Twenty-five local business owners and the deputy major attended the first event.

2. Improve the living environment.

BOS is influencing the Mayor's Air Pollution Task Force. A partnership between BOS and Liverpool City Council's departments of public health and environment allows residents to contribute to the development and implementation of a citywide air pollution strategy.

BOS is also planning a citizen science project to look at local sources and levels of air pollution. Findings will be used to develop an awareness-raising programme about air pollution with local schools in partnership with the City Council's departments of public health and environment.

BOS uses YouTube and social action (such as wearing dust masks in the high street) to highlight the health risks of polluted air. Currently, it is mobilizing residents and schools to participate in the production of a local film to enthuse the community to get involved in action to tackle air pollution.

3. Improve social resilience.

A reading group was set up with around 20 residents purchasing and reading the first novel. The reading group is registered with Readinggroups.org, which provides access to the groups' contact details, and it has an active Facebook group.

Resident advisers are networking across all nine neighbourhoods in the Programme, providing opportunities to network, socialize, develop skills and share resources.

4. Improve community governance.

BOS was invited to be part of the Steering Group of the Liverpool Combined Region Air Quality Study: currently the only group representing the voice of local communities.

Dialogues are underway with a wide range of local agencies to identify opportunities for residents to voice concerns and influence decision-making and other processes in the area. These include: the Mental Health and Wellbeing Hub, City Life, Business in the Community, the Police Service, the Fire Service, the local authority and local businesses.

Sefton: "Stop loan leeches"

Indebtedness is an endemic issue across the United Kingdom. It is twice as common among individuals living in households in the poorest 20% of neighbourhoods than it is among those in the 20% wealthiest areas. Indebtedness is closely linked to poor health (12,13). Echoing these statistics, many involved in early discussions in the Neighbourhood for Learning in Sefton raised concerns about the growing issue of unsecured debt and the broad ranging impacts this was having locally. There was also concern that many people did not know about local services providing advice and support on managing debt.

As in other NRP neighbourhoods, the Local Oversight Group has brought together residents, the local council, the COREN organization (Sefton Council for Voluntary Services) and key organizations and services concerned with indebtedness and economic resilience. Residents have conducted local inquiries and identified activities that could address some of the problems including: improving signposting and access to advice and support services and providing information and training. Findings from the resident-led enquiries have informed the development of a local action plan. Some of the actions subsequently undertaken or scheduled were included in the plan. Others arose through opportunistic or serendipitous collaborations.

There were several early actions.

- Build connections between organizations providing services and support for those having problems with debt.
- Provide training by the National Illegal Money Lending Team (IMLT) for volunteers at a local migrant workers group. This has focused on how to recognize when someone may be a victim of illegal money lending (loan sharks), how to assist them and how to report illegal money lending.
- Support delivery of a school-based drama workshop highlighting the dangers of gambling and raising awareness of loan sharks, with funding from IMLT and the Stop Loan Sharks Community Fund.
- Develop a pilot resource, incorporating gambling awareness training for staff, a drama-based workshop for young people and sign posting to counselling and advice services.
- Restrict access to high interest pay-day loan websites from public computers at libraries etc.
- Co-produce a short film to raise awareness of the dangers of illegal money lending by illegal money lenders called "Stop Loan Leeches", which won an award (Fig. 7). This involved collaboration between Sefton Council, the Migrant Workers Sefton Community group, the England Illegal Money Lending Team and Handstead Films. The video is available in six languages and was distributed via YouTube (14).

These actions have the potential to enhance economic resilience by building capacity in debt advice in the area, raising awareness about debt and the problems it can cause and increasing access to high-quality advice and support. Training for volunteers from the migrant workers group is enabling them to better support victims of illegal money lending. Gambling awareness training that is planned to take place in education organizations will help staff identify the signs of gambling problems and signpost people to available services. Resident advisers, who are also able to support others in accessing debt advice services, attended a workshop to support delivery of advice about new welfare benefits rolled out in the area, and debt training is also planned for them.

There is also evidence that the NRP in Sefton is enhancing social connectedness. Early signs suggest that local debt and advice service providers are forging new connections with each other. As in all the other neighbourhoods, Sefton's resident advisers network with residents from other NRP neighbourhoods, providing opportunities to socialize, develop skills and share resources. There is also evidence that findings from the resident-led enquiry are beginning to have an impact on community governance locally, with one service responding to these findings by providing better information to its staff on what to expect when someone approaches services for advice on debt.

Lessons learnt

NRP is in its early days. Nevertheless, a number of lessons can be distilled regarding the power of system resilience at the neighbourhood level. Much work in the neighbourhoods has been underway for less than two years. There are no quantitative findings on impacts. However, preliminary insights from observations, interviews and informal conversations point to the potential power of increasing resilience in neighbourhood systems as opposed to the narrower/separate focus, more common in public health, on community and/or health system resilience. Comments from participants involved in the Programme provided below illustrate these positive experiences, but they also point to significant challenges that remain to be addressed (Fig. 4.3).

Fig. 4.3. Partners' comments about their involvement in the NRP

"It really is a community owned programme in system decision making"

"I's been a journey!... more sales orientated than envisaged, getting partners, senior colleagues and community orgs and memebers to see the value"

"Residents [are] able to actively take part in research and audit activity that they have identified"

"The LOG meetings have attracted a number of 'added value' projects th the area as a result of bringing different partners to the table"

"Understand the programme but whether we'll achieve what we envisage???"

"Provides safe space for stakeholders to share their experiences of what's happening in the area, which is great for connecting to other initiatives"

"Providing training and supprt to local residents in this way is great"

"The major selling point for me is involving local people"

"It is fantastic to be working directly with residents who really care about their nighbourhood"

"The work supports and compliments our programme - adding greater value"

"The evidence reviews and survey [have] proven useful for so much officer time at a time of tight budgets – a lot more time than we initially envisaged"

"Roles come up again and again and still not clear who should be doing what"

Source: adapted and reproduced with permission from CLAHRC NWC.

Collaboration between members of the academic team, the COREN facilitator and local authority partners has been central to develop and maintain momentum. In each neighbourhood, these people have acted as "brokers" (12), creating new participative spaces with different more inclusive power dynamics, fostering new dialogues to connect previously disconnected groups and activate existing local, regional and national resources to produce tangible, positive effects. Their involvement in the Programme has also pushed people to look at the neighbourhoods in which they live and/or work in a holistic way: to take a systems perspective moving beyond individualistic, community only, or narrow sector-specific interventions, which often fail to achieve significant long-term transformation.

The communities participating in the NRP were not ready (in traditional community development terms) to engage in local action for change. The residents who have become advisers to the Programme are not those who would usually participate. Similarly, the local businesses that have been involved have typically not been engaged in similar civic activities in the past. Discussions in the local oversight groups and between core workers often revolve around how to engage with system actors – residents and others – who are less vocal, less ready to claim their rights, to articulate demands, to insist on participation and demand accountability to "begin to gain more choices" (13). In Sefton, for example, the local programme has focused some activities on the impact of debt and illegal money lending on migrant workers. In another neighbourhood, the focus has been engaging with tenants of privately rented accommodation with the aim of improving the quality of accommodation in this sector. This neighbourhood has also considered ways to engage with private landlords and private sector letting agencies. These groups of tenants and migrant workers are often particularly marginalized and transient and are less likely to feel secure enough to report problems for a number of reasons including fear of eviction and/or lack of formal documentation.

Work on the NRP is demanding for all those involved. Members of the core academic team have had to get to know the multiplicity of networks in the neighbourhoods and their historical scars, to listen to, and build rapport with diverse groups and organizations. They have had to help design ways to change the collective mind-set of residents and those in the public, private and community sectors delivering services in the neighbourhood: shifting it from silo/community to system thinking and working. The academics are often required to balance methodological rigour with the need for accessibility, appropriateness and local ownership.

The local government partners, particularly those on the Programme management group, have shown a strong sustained commitment to the work. They are often juggling institutional pressure to hit targets and ever increasing workloads as public finances shrink, with ambitious aspiration for what could be achieved in the neighbourhoods. They, and other professionals involved, are also a conduit for new systems approaches to work within their own organizations. Grasping the concept of system resilience, some have been observed to correct colleagues: "this is a system resilience programme not a community development project, we work like a system, the purpose is not to consult residents but to engage them throughout the process".

Developing system approaches to resilience is not an easy option. NRP demands time, energy, commitment and imagination from all involved – commodities in relatively short supply in the current political and economic climate in England. However, the evidence to date highlights multiple ways in which the Programme is releasing the collective adaptive capacity of residents, community organizations, public and private sector service providers, policy-makers and local politicians to act to reduce the upstream drivers of health inequalities. Although the main responsibility for addressing these drivers must lie with national governments, much can be done locally. NRP is beginning to show that action to address social and commercial determinants of health inequalities that can be challenged locally will be more effective if it focuses on developing resilient neighbourhood systems not resilient communities or organizations alone. The Programme is also producing a cadre of people (lay and professional) across the northwest coast area of England better informed about the upstream drivers of health inequalities, taking action locally with potential to contribute however modestly to a reduction of these inequalities and willing to challenge those with the power to address upstream drivers that are outside local control.

Acknowledgements

The authors are grateful for the contributions from the CLAHRC academic team (Dr Ben Barr[30], Dr Vivien Holt[31], Ms Koser Khan[31], Dr Adele Ring[30], Ms Gill Sadler[31], Dr Glenn Simpson[30], Ms Fiona Ward[31] and Ms Paula Wheeler[31]); the local authority members of the CLAHRC Public Health Theme Management Team; and resident and other members of the local oversight groups in the Programme neighbourhoods.

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NRP is funded by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care North West Coast (NIHR CLAHRC NWC). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

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United Kingdom (Wales). Strengthening resilience through the Early Intervention and Prevention: Breaking the Generational Cycle of Crime project

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Abstract

This inspirational example from Wales in the United Kingdom addresses the issue of childhood experiences, both negative and positive, and their impact on health and well-being. It shows the current efforts in Wales to maximize positive and prevent negative childhood experiences by focusing on strengthening resilience. The approach chosen is based on a comprehensive understanding of how adverse childhood experiences (ACEs) can impact a variety of health and well-being issues both during childhood and later in life. The example shows that building resilience to address ACEs requires a holistic and intersectoral approach to appropriately meet a wide range of emotional and physiological needs. Such an approach should also be characterized by consistency and appropriateness of supportive measures including extended opportunities for learning and growth for children that experienced ACEs. The authors maintain that resilience can be strengthened only when such a holistic and intersectional approach that creates a supportive environment for health and well-being is actively sought and implemented.

Issue

Internationally, demands on policing are changing as crime rates decline with associated increases in issues of welfare, public safety and vulnerability (1–3). Due to increasing awareness of vulnerability, the police commonly respond to individuals who have experienced, or are experiencing, ACEs. ACEs are stressful events that directly harm children (e.g. physical abuse) or are present in their home environment (e.g. parental drug misuse and incarceration) (4). These adverse events have been associated with health-harming behaviours, and increased morbidity and mortality (4–15). Exposure to trauma in childhood can also contribute to poor school performance, lower levels of employment and criminal justice outcomes (4,16).

In 2015, the first national Welsh ACE survey found that almost half (47%) of the population had experienced one ACE, with 14% experiencing four or more (4). Compared to individuals who have experienced no ACEs, those who experienced four or more were 14 times more likely to be a victim of violence and 15 times more likely to have committed violence against another person at some point in the 12-months preceding the study (4).

Reducing childhood adversity is critical to preventing detrimental outcomes later in life. The negative impact of ACEs can however be mitigated through strengthening individual resilience (6,17) and community resilience (18). This approach supports the Sustainable Development Goals 3 and 10 set out in the United Nations 2030 Agenda for Sustainable Development, which aim to ensure healthy lives and promote well-being for all at all ages, and to reduce inequality within and among countries (19). Resilience refers to the ability to achieve positive outcomes despite difficult circumstances (20). It can be enhanced by promoting protective factors in children such as having a caring and supportive relationship with an adult, believing that one can overcome hardship, feeling grounded in traditions and having the skills to regulate emotions and behaviours in order to overcome stressful circumstances (Fig. 4.4) (20).

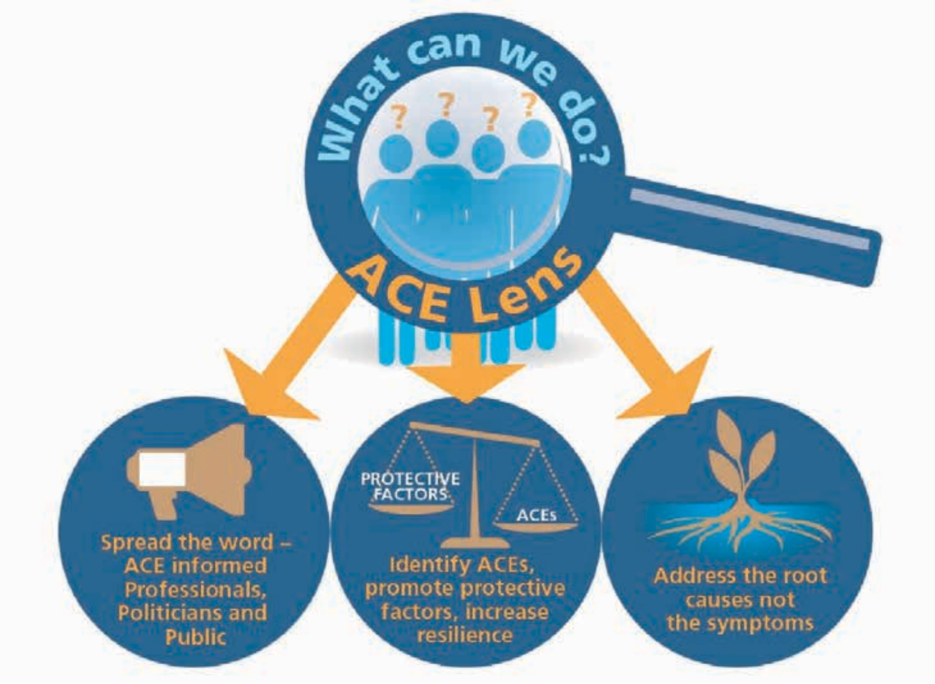
An early intervention approach is one which seeks to provide timely support to children and families who face problems in order to improve their life chances (21). Building resilience and responding early to those who have experienced ACEs has the potential to benefit a range of services (e.g. criminal justice, health and education). In England and Wales, an estimated £17 billion is spent a year on late intervention (22). Collaborative early intervention programmes are likely to have significant cost benefits (23–27). For example, for every £1 spent on parenting programmes to prevent conduct disorder in Wales, £8 is returned over six years as a result of savings made to the health, education and criminal justice services (26). Investment in interventions that target early years and take a preventative approach has been recommended as they are likely to be the most effective and reduce costs associated with health and social problems later in life (27). Preventing ACEs contributes to reducing health care costs, costs to society and the overall economy and thus to sustainable development in Wales and the Well-being of Future Generations (Wales) Act 2015, specifically "a more resilient Wales" (28).

Fig. 4.4. Building blocks of resilience

Source: reproduced by permission of the publisher of *Supportive Relationships and Active Skill-Building Strengthen the Foundations of Resilience* (20).

It is hoped that applying an ACE lens to policing will support staff to work upstream in a more preventative way. An ACE lens works to address the root causes of problem behaviour and support protective factors (Fig. 4.5).

Fig. 4.5. An ACE lens



Source: Public Health Wales NHS Trust.

Action

The Early Intervention and Prevention: Breaking the Generational Cycle of Crime project was set up to understand how public health, in collaboration with other sectors, can build resilience at individual and community levels. Strengthening resilience in this way closely aligns with the Health 2020 policy priority areas one (investing in health through a life-course approach and empowering people) and four (creating resilient communities and supportive environments) (29).

The project aims to better understand the current approach taken by South Wales Police (SWP) and partners in response to vulnerability, and to develop a portfolio of training and interventions that enables the approach to become more effective. Protecting those who are vulnerable is a priority area for SWP and it strives to take prompt, positive joint action to address issues early (3). The project is based in South Wales and funded through the Police Innovation Fund.[33] It is a collaboration between Public Health Wales, the Police and Crime Commissioner for South Wales, SWP, the National Society for the Prevention of Cruelty to Children (NSPCC), Barnardo's and Bridgend County Borough Council.

As part of the project, Public Health Wales conducted mixed methods research to understand the police response to vulnerability by SWP and associated partners (30,31). The research found varied capacity across the police force to effectively assess and respond to vulnerability and that traditional policing methods, training and systems were not designed to meet the scale of vulnerability demand that is now encountered. Although SWP staff recognized that responding effectively to vulnerability was a police force priority, their understanding of trauma and the impact that ACEs can have on life outcomes was incomplete. The research also highlighted the adverse impact that responding to incidents has on staff well-being and a limited knowledge of the formal support available to staff when dealing with trauma (30,31).

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[33] The Early Intervention and Prevention: Breaking the Generational Cycle of Crime project (Reference 2016-039) was awarded two years of funding from the Home Office, Police Innovation Fund.

A number of challenges with working cross-organizationally for the response to vulnerability were also identified, including a limited knowledge of partner agencies' protocols, different working hours and a need for a shared understanding of vulnerability across services. Social services reported receiving a large number of safeguarding referrals from the police, an analysis of which indicated that the majority of police referrals result in no further action by social services (30,31). The findings of the research demonstrated that traditional policing processes that take a reactive and crime-orientated approach need to be adapted to become community focused and allow police to work upstream in their response to vulnerability. The research demonstrated that SWP staff require additional training to develop their understanding and skills in how to communicate and work effectively with vulnerable community members. Furthermore, the research highlighted a need to change the current referral process as the majority of police referrals received no action by social services due to their high threshold level.

Changing the process could allow SWP to work proactively with partners to ensure individuals who are at risk of poor outcomes receive support at an earlier stage of vulnerability and risk in order to prevent further escalation of harm. Five recommendations were developed to increase early intervention and prevention activity taken in response to vulnerability and are currently being implemented in two pilot areas within South Wales. These included piloting a **training programme using an ACE-informed approach to policing vulnerability** and piloting a **structured multi-agency, early intervention approach to vulnerability**.

Impact

Impact on policing

In one pilot area in South Wales, operational police staff received the ACE-informed approach to police vulnerability training. The aim of the training was to ensure police have the right skills to respond to vulnerable people at the earliest opportunity including skills in effective communication, de-escalation of emotions and grounding techniques. The training consisted of two sessions which covered the impact of trauma on development, applying trauma-informed practice to policing, staff well-being and advantages of multi-agency working.

An evaluaion of the training conducted by Public Health Wales found that participation led to a greater awareness of ACEs and improved attitudes towards trauma-informed care (32). Generally staff held very positive views about the training and identified positive impacts on policing such as recording more detailed information on safeguarding referrals. Participants also identified how the training may influence the way they interact with children.

> *You've got to talk to them on their sort of level, so rather than going in all guns blazing so to speak, being that like scary figure of authority... you actually just want to have a general conversation with them, to kind of build a rapport.*

Furthermore, due to the training, staff reported that they were more likely to seek both formal and informal support after attending a traumatic incident. The findings are useful for informing how staff can be trained across other police forces in Wales and the rest of the United Kingdom, and how this type of training can be translated to different sectors. For example, participants indicated a preference for the training to be delivered by professional social workers in a relaxed environment. A follow-up evaluation is currently underway to assess the long-term change in attitudes toward trauma-informed care and explore whether an ACE-informed approach has been embedded into police practice.

In addition, a structured multi-agency, early intervention approach to vulnerability is being piloted in two areas in South Wales.

From left, South Wales Police Deputy Chief Constable Richard Lewis visits the structured multi-agency early intervention pilot in Maesteg, South Wales, with Police Community Support Officer Emmanuel, Sergeant Bradley and Steph Sibanda (NSPCC).

The approach has been set up to allow police and social services staff to work together to identify vulnerable families and ensure those who present with low-level vulnerability get help when they need it. The pilot focuses on supporting those with low-level vulnerability to ensure they receive prompt intervention to prevent problems from escalating and becoming higher risk. A police community support officer will be allocated to each case and will work to build a rapport with the family. The officer and a social services worker where appropriate, will aim to increase children's resilience by providing caring support and referring them to programmes that can develop their coping strategies, help manage relationships and build confidence. A police community support officer reflecting on the new approach commented:

> *…I do like, actually having follow up with the families. It is nice, I mean, especially if it's something like domestic violence, you know, it's nice to actually give them a ring, you know, a week or two down the line, how's everything been? You know, because you're building a relationship with that person, you know, and that phone call could make a difference, you know a massive difference to that family's life, especially if they're a repeat victim.*

The safeguarding referral process between police and social services has been adapted to increase communication between the agencies, improve information sharing and develop joint action plans where appropriate. The approach seeks to support families who may not have previously received an intervention as their circumstances do not meet the threshold for intervention from social services.

The approach is under evaluation, with interviews conducted with staff at SWP and social services to explore their experiences of the partnership process, the impact it has had on members of their community and whether it would be feasible to roll it out to other areas. A member of senior management at SWP reported that the approach so far has

> *had some really good indicators of progress...[and] when we look at outcomes such as improved relationships, improved data sharing, improved joint decision-making about risk, they've all been successful. Whether or not they've had the desired effect on that intergenerational cycle of crime, we can't say, but all the right markers and flags are there. So, certainly encouraged by the direction of travel and some of those outcomes that we can measure, I'd say, yes, that had been successful.*

Impact on partner agencies and sustainable development

The Early Intervention and Prevention project has worked with partner agencies to raise awareness of vulnerability and promote a multi-agency approach. In Wales, the Well-being and Future Generations (Wales) Act 2015 and Social Services and Well-being (Wales) Act 2014 have created an opportunity to enable closer partnership working and to take a preventative approach (28,33). Training in ACEs has been developed and is being delivered to criminal justice, housing and school staff within South Wales. The training programmes aim to provide staff with the skills and knowledge to enquire, intervene and respond to vulnerability and prevent the transmission of ACEs to the next generation. An improvement in partnership working between the police, schools, probation and housing is expected as a shared understanding of ACEs and vulnerability is established.

Training within the housing sector is seeking to improve understanding of ACEs and impact through the life-course; increase understanding of the impact of ACEs on vulnerability and the risk of homelessness and how a trauma-informed approach can help; outline tools to improve effective engagement with vulnerable tenants and their families; and explore improved partnership working between agencies to support individual and families in need. An evaluation of the housing training is ongoing. Some participants commented on how the training will influence their practice.

> *I think having had the training it will be in the back of my mind to…consider ACEs and whether you know, alarm bells start ringing and I think hang on a minute, we need to get some sort of intervention in here because things are happening so I think it does, you know and it will trigger that…when I go out on my visits and so on.*

Housing staff will work to strengthen resilience of tenants through applying an ACE-informed approach to identifying and supporting vulnerable tenants, helping them to access support services, and contribute to better multi-agency working and an improved ACE-informed system. The goals are to maintain stable tenancies, reduce evictions and homelessness, and help to prevent intergenerational transmission of ACEs.

In the education sector, an ACE-informed whole-school approach is being piloted in three primary schools. The approach seeks to understand the schools' readiness to become ACE-informed and develop an action plan to identify the support and resources needed to work in a trauma-informed way. It aims to support all school staff in becoming ACE-aware and to use their understanding of ACEs to intervene at the earliest opportunity. A teacher reflecting on her own practice after attending the training said

> *I think definitely thinking more about if a child is showing any adverse behaviour in school thinking about what could be behind it and trying to understand them a bit more so you're more sympathetic. So you deal with them differently and trying not to look at the behaviour but trying to think about the child.*

Staff will work to strengthen resilience in children by providing them with stable and supportive relationships, creating a safe and calm environment and building their skills in emotion regulation. The long-term goals of the whole-school approach are to improve pupil attainment, increase pupil well-being and reduce the number of school exclusions. The learning from the ACE-informed whole-school approach should also inform a broader programme of work on ACE-informed schools across Wales.

Research is also being conducted to explore the prevalence of ACEs within an offender population. The research will contribute knowledge on the association between ACEs and offending, and will provide an understanding of outcomes for the children of offenders, thus identifying risk factors for families. The research will contribute evidence which can be used to inform interventions aimed at breaking the intergenerational transmission of ACEs, violence and crime, and reducing current and future offending. Training within the probation and prison service is hoped to increase the understanding of ACEs among staff and improve offender compliance through better service user engagement as a result of staff working in a trauma-informed way.

Working in a multiagency trauma-informed way to respond early to vulnerability and prevent the transmission of ACEs across generations supports sustainable development in Wales. The project aims to reduce the cost of ACEs for other sectors, such as health and social care, and the overall economy which has been estimated to be £60 billion in England and Wales per year (26,27). The project is an example of an action to support implementation of the newly adopted Roadmap to implement the 2030 Agenda for Sustainable Development, building on Health 2020, the European policy for health and well-being (34). It works to ensure no one is left behind by preventing disease and addressing health determinants through promoting multi- and intersectoral policies throughout the life-course; and establishing healthy places, settings and resilient communities.

Lessons learnt

This example demonstrates how an ACE lens can be applied to policing in order to build individual and community resilience in those who are vulnerable. The project is the first of its kind to trial and test an early intervention, multi-agency approach that addresses vulnerability with a life-course perspective. There has been key engagement from a range of partners (e.g. policing, local authority, education, housing and criminal justice) that are all aiming to work in a trauma-informed way and intervene early to address problems before they escalate.

An open and transparent approach from SWP allowed researchers to explore the system for the response to vulnerability by the police and other agencies. This allowed for development of a series of recommendations for action in order to ensure that the police and other partners respond to vulnerability-related demand in a more effective and efficient way. SWP supported the recommended changes and the adapted early intervention process. It is hoped that this will enable better communication and joint visits between social services and police officers and that families presenting with low-level vulnerability will now receive support to address the concerns that are present and prevent them from becoming higher risk. This pilot demonstrates how police practice can be adapted, and the evaluation will advise whether it has been effective and how it could be sustained over time.

Evaluation of the ACE-informed approach to police vulnerability training demonstrated clear benefits as it provided staff with increased confidence in how to respond effectively to vulnerable people. In response to research findings (30,31), this training addressed officer well-being and may have in turn increased workforce resilience by increasing the propensity for staff to seek personal support after attending a traumatic incident. Before the training, participants were not fully aware of the support available to them, and some reported that the demands of policing had impacted on their mental well-being and affected their work-life balance. Establishing a resilient workforce could achieve increased job satisfaction, improved well-being and fewer sickness days. Addressing workforce resilience through training is likely to be beneficial in other services where staff attend traumatic incidents. The evaluation offers transferable learning for how this type of training can be delivered in other sectors and advises on the appropriate style of delivery (i.e. interactive, relaxed environment, delivered externally and tailored to the participants' role).

Public Health Wales, the four Police and Crime Commissioners and a range of partners across Wales have used the work in SWP to secure further funding from the Police Transformation Fund[34] which will enable the further development of this multi-agency, ACE-informed approach at an all-Wales national level. The three year programme has four key objectives and will work with partners to develop:

1. a competent and confident workforce to respond more effectively to vulnerability using an ACE-informed approach in policing;
2. organizational capacity and capability which proactively meets changing demand;
3. a single integrated entry point for vulnerability that signposts, supports and safeguards encompassing police, welfare and health services and is available 7 days a week, 24 hours a day; and
4. a whole-system response to vulnerability by implementing ACE-informed approaches for operational policing and key partners.

Ultimately, police and partners will have the right skills and resources to work together to better support those who are vulnerable and identify opportunities to build resilience to protect individuals from the negative impact of trauma.

Acknowledgements

This project has been funded through the Home Office Police Innovation Fund and South Wales Police and Crime Commissioner. The authors would like to thank South Wales Police and partners for their participation in the project and for their time to complete research interviews and/or questionnaires.

Thanks also go to Dr Mariana Dyakova (International Lead and Deputy Director, Policy, Research and International Development, Public Health Wales) and Professor Mark Bellis (Director, Policy, Research and International Development, Public Health Wales) for their comments on earlier drafts. The authors are grateful to Dr Charlotte Grey (Policy, Research and International Development, Public Health Wales) for her valuable comments and support in report production.

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[34] The all-Wales ACE approach to policing vulnerability programme has received three years of funding from the Home Office, Police Transformation Fund.

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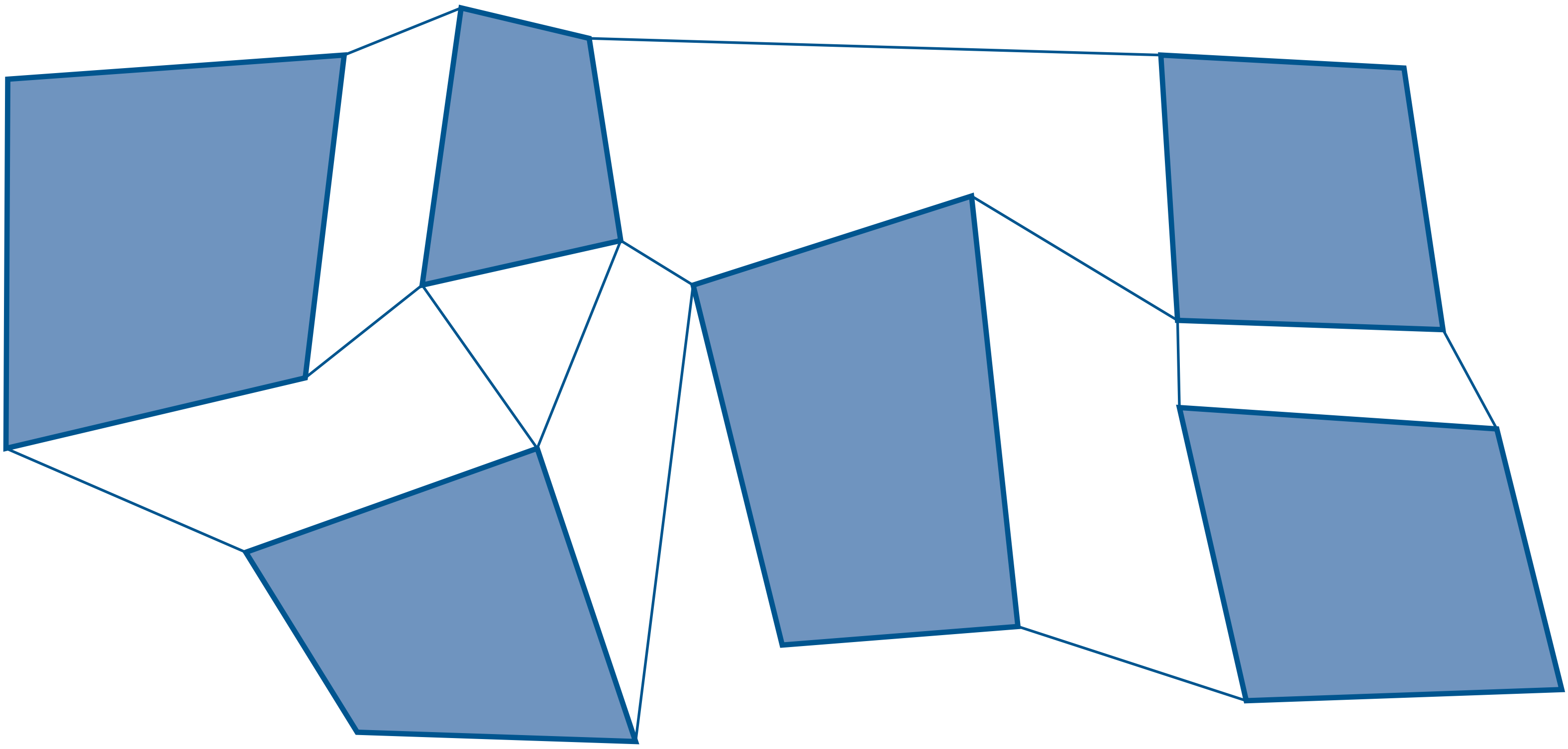
Part 5. Building resilience outside Europe

Three testimonies on building resilience at community and local levels were selected as they may be of interest to the European audience. The first is about the Australian experience in building resilience in dispersed rural communities. The others are Canadian experiences in building resilience in a community that was struck by a man-made disaster that caused many casualties, an ecological disaster and social trauma. These examples relate to similar situations on the European continent.



Australia. Community resilience and interventions: lessons from Queensland

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Abstract

This set of inspirational examples is drawn from participatory research with communities and some organizational partners in three parts of Queensland, Australia, over the past decade. It highlights communities self-organizing to enhance their resilience, and introduces tools they or their organizational supporters can use or adapt to assist in building this resilience. It is not specifically focused on health, but on the social, ecological, economic and institutional contexts in which health thrives or can be threatened. The lessons learnt from this Australian experience and the work in the field of community resilience carried out by the author over the years are very relevant to both the intersectoral approach proposed by Health 2020 and the SDGs.

Issue

This narrative starts by outlining an understanding of resilience and how it has shaped work with communities in Queensland, Australia. It treats resilience as an interdisciplinary concept, potentially applying to any unit of society and environment, from the individual to global. Multilevel supportive relationships are important to individual, community or system resilience. For instance, this Compendium is partially focused on how policy-makers and other organizational supporters (at regional, national or international levels) can promote community resilience.[36]

Psychology and mental health scholarship on individual and later community resilience present the idea of focusing on people's strengths rather than their limitations. The social-ecological systems body of literature presents resilience as a property of complex adaptive systems that behave in dynamic ways, often with feedback (multiple influences). This literature treats social-ecological systems as interdependent (coupled) systems of humans and nature. Whereas that literature focuses on nature, all physical environments, including natural, farmed and built environments should be considered. Further, people, at any social scale, may have specified resilience – resilience to a specific type of shock or change, such as financial crisis or flood – or generalized resilience: capacity to cope with or even thrive through many types of stress.

Both these bodies of literature have limitations. For instance, the social-ecological systems literature remains naïve on the many available social science concepts, for instance, by underplaying social structures such as power relationships. As Bene et al. (1) point out, resilience is not a pro-poor concept, in the sense that it does not substitute for poverty reduction and other efforts to meet human needs. Meanwhile the psychology–mental health body of literature mentions environment often, as a contextual influence in a person's resilience. However, it is treated as a social and seldom a physical environment despite, for example, the effects of poor housing or the benefits of interaction within green spaces in stress and coping.

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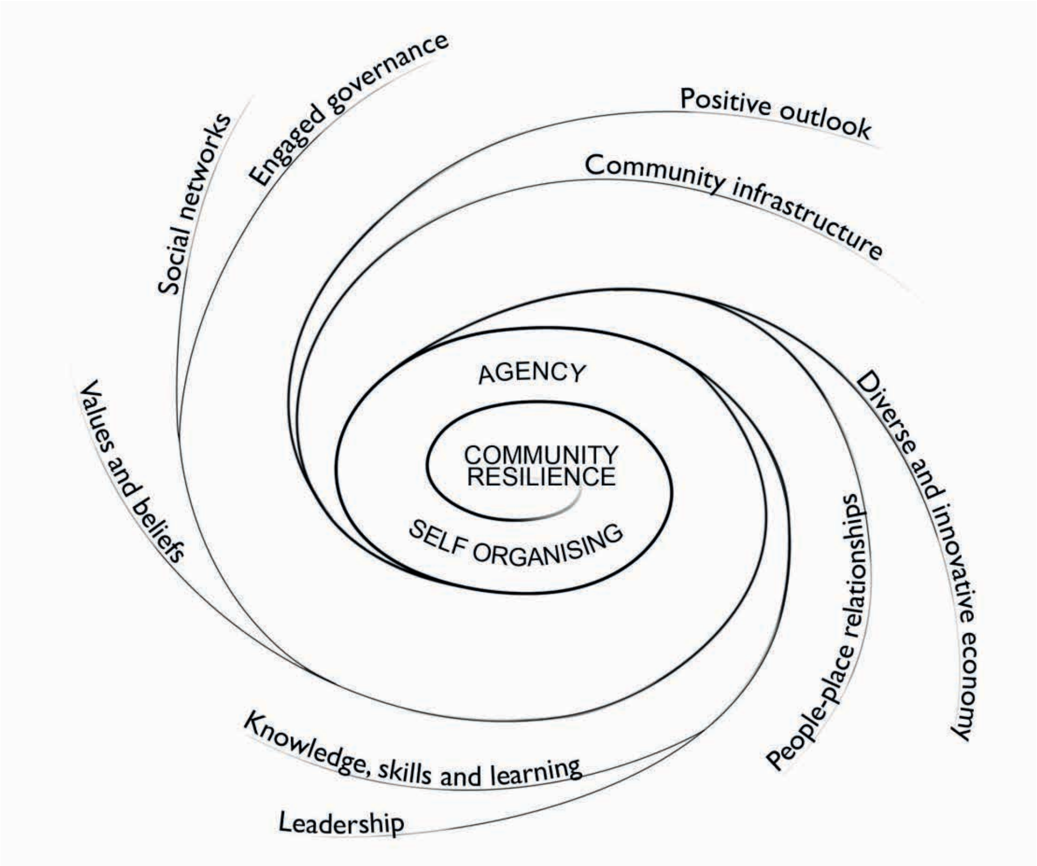
[36] Some readers may prefer a side-by-side image of these relationships rather than the hierarchical image implied by the social-ecological systems literature idea of multilevel systems.

Communities are recognized as both place and interest, while noting that communities of place are more obviously influenced by (and influence) their physical environments. A community is a social unit featuring common values and interests, interactions among its members and constituent groups, and usually a shared history. A community is more than the sum of its individuals and households. It need not be harmonious; divisions and debates (and the ability to overcome them) may be constructive in meeting change.

While the term "community resilience" has become strongly identified with disasters, this field can be treated as a keen adopter of the idea, rather than disasters being the main or only type of stress or shock for which resilience is relevant.

Community resilience is summarized in Fig. 5.1 from Berkes & Ross (2), a synthesis of and additions to research that had identified characteristics of resilient communities. Resilient communities share a number of characteristics identified in numerous studies, but resilience is more than that. Some process of self-organizing and agency is needed to convert these capacities into an active process of preparing for and meeting crises and challenges, even transforming positively in the process. Brown (3) identifies resilience as a capacity (adaptive capacity), process and outcome of undergoing, actively engaging with and adapting to change.

Fig. 5.1. Community resilience as a function of the strengths or characteristics identified as important, leading to agency and self-organization



Source: reproduced by permission of the publisher, Taylor & Francis Ltd, of Berkes & Ross (2).

Perhaps because of its origins in research on regions rather than communities, the social-ecological systems literature emphasizes a collaborative form of governance (adaptive co-management) as the key to managing these complex systems. This combines adaptive management, a systematic, cyclical method for continual improvement rather like action learning, with multiparty collaboration. Since usually no single party has sole influence over a system, participants must collaborate to be effective.

Action and impact

In order to show how the understanding of resilience outlined above is utilized in practice, three examples are briefly highlighted. These examples reflect resilience in a variety of circumstances: climatic threats (Stanthorpe and South East Queensland), and ecological and livelihood change (Far North Queensland). While focusing on community resilience, they reflect the relationships between individual, group and community resilience (Stanthorpe), and communities and regional management (Far North and South East Queensland). Above all, they emphasize community self-organizing and agency, ahead of managed interventions, and suggest that where managed interventions are attempted, they should be undertaken collaboratively with communities.

Stanthorpe, Queensland

The small rural hill town of Stanthorpe and its surrounding rural area has a population of 5780 (Australian Bureau of Statistics 2016 census). Its cool temperate climate and soils are favourable for agriculture and enable rapid adaptation when fruit orchards are destroyed by hail or fire; vegetables can maintain income until orchards can regrow. It is also known for its natural beauty and has a number of national parks attracting tourism. The area was first developed for pastoralism, displacing the original Aboriginal owners, then discovery of tin attracted miners. In 1882, the railway brought German settlers. As mining declined, the miners were encouraged to diversity into fruit growing, leading to this region becoming known for its wide variety of fruits, wines and vegetables. Italian migrants followed both world wars. Since, Dutch, Croatians and Thai add to the cultural mix. Stanthorpe people are proud of their cultural diversity, and point to the mutual learning and intermarriage that brought respect over extended periods. Nevertheless, according to national indices, the town and area are among the most disadvantaged within Australia.

Participatory action research study with the community in the late 2000s (4) showed Stanthorpe to be a well-connected, self-organizing community. It had many community organizations, mostly knowing and assisting one another, and a high level of volunteering. Community members highlighted how people from all over the district, even strangers, would turn out to help any farm affected by hail, since fruit picked within 24 hours could still be sold. The community had one, part-time community developer, who helped to link the many organizations through quarterly meetings. Individual, group and community resilience were mutually influencing: individuals contributed to and drew from networks of social support, though it was possible for certain individuals, such as those with disabilities, to be less well connected and supported. Community members attributed the community's positive outlook to learning from the way multicultural farming families overcame set-backs.

From the 11 concepts identified by the study (4) as contributing to the people of Stanthorpe's community and individual resilience, a toolkit was produced, designed to help other such communities build their resilience (5). Groups and organizations within or possibly external to a community were suggested to add a resilience focus to their existing role, rather than trying to set up a new initiative and risk separating resilience building from the community's many other activities. The toolkit is designed to stimulate ideas, not provide recipes. It explains each of the 11 concepts and offers ideas as to how a user can work with individuals, groups or the whole community to build resilience. For each concept, the toolkit also provides some Stanthorpe community perspectives, with quotations and photographs taken by Stanthorpe high school students as part of the verification process, a brief literature review and examples of practices used elsewhere.

The 11 concepts (5) are:

1. social network and support
2. positive outlook
3. learning
4. early experience
5. environmental and lifestyle
6. infrastructure and support services
7. sense of purpose
8. diverse and innovative economy
9. embracing differences
10. beliefs
11. leadership.

Far North Queensland

The coasts, mountain range and plateau of Far North Queensland form a complex region, well known for its Great Barrier Reef and Wet Tropics (rainforest) World Heritage areas. From a resilience perspective, it has concerns for cyclones and floods, climate change, water quality affecting the Great Barrier Reef and rapid regional change. A collaborative study in the late 2000s studied social resilience to help five regional organizations – government, non-government, environmental, social or both – to identify how they could support and monitor social resilience in their regions.

Based on partners' advice about key change processes in the region, an additional six cases were studied: five about communities dealing with environmental, economic or demographic change, and one institutional study of the way the Aboriginal organization works to enhance the resilience of their lands and peoples (6). All showed remarkable self-organizing and agency. In the case of dairy deregulation, which led to nearly a 60% drop in the number of dairy farms, the local dairy company's building became a hub where those affected could drop in to receive and give social support and interaction. The company had also held at least one workshop to help farmers to recognize the process they were going through and look after themselves. In response to a major environmentally and economically threatening outbreak of the crown-of-thorns starfish, tour operators, fishers, scientists and environmental managers collaborated to work on the problem.

Girringun, an association of nine Traditional Owner groups of the southern part of the region, is a standing example of agency and self-organizing. Girringun formed in 1994 out of a protest about national park matters. Twenty-five years later it continues to provide a focus for its members' efforts to promote their culture, assert their rights as Traditional Owners and environmental custodians, as well as develop social and economic development programmes.

It partners creatively with government agencies in environmental management. It initiates many innovative programmes, such as its Wishbone project with a high school, which promoted cultural understanding within the school environment (6).

Similarly to the Stanthorpe study, this project identified key factors (with collaborating processes prominent across them) in promoting social resilience as:

1. people–place connections
2. knowledge, skills and learning
3. community networks
4. engaged governance
5. a diverse and innovative economy
6. community infrastructure.

Advice to the regional organizations seeking to understand, monitor, and perhaps enhance social (or community) resilience was that they had three options (7).

1. Know (acknowledge) resilience. They could pursue their existing mandates in consciousness of the resilience characteristics in their regions, without trying to intervene.
2. Use it. They could take advantage of resilience characteristics in their management strategies.
3. Grow it. They could go further to pursue organizational mandates in a new way that enhances social-ecological resilience.

For example, an environmental management organization could identify social networks and place attachment (know resilience). It could also engage community groups in mutually relevant landscape endeavours (use it); or seed and support new community-based groups (e.g. landcare groups) where social networks are needed (grow it).

The Cassowary Coast, home of an endangered bird, shows how activities and dissemination of knowledge can build a stronger sense of and pride in place, make people feel part of their area and help them to treasure and want to protect the natural resources there.

Monitoring advice focused around the six resilience concepts and identified proxy measures that were easily collected and mapped from publicly available statistical data while recognizing its deficiencies (7).

Building local knowledge and networks for climate change adaptation in South East Queensland

Two issues confronting climate change adaptation are the absence of locally relevant information, since climate models so far are only capable of working on large regional scales; and engaging and activating communities, which can easily feel disempowered by the dominant physical science, government and media discourses which suggest expert-driven, top-down approaches to adaptation.

The field location to develop a process for jointly addressing these issues was South East Queensland, including the hinterland and city of Queensland's capital, Brisbane, and the ecologically sensitive Moreton Bay, a marine national park. This region is particularly vulnerable to climate change. It is forecast to become hotter and drier; storms and rainfall are likely to intensify, and the sea level will continue to rise. Increasing extremes in climate place added pressure on already constrained resources. Even now, extreme weather events such as floods endanger biodiversity, damage infrastructure, and threaten people’s lives and livelihoods especially for the vulnerable (8).

A transect was chosen connecting a rural area including both marginal and highly productive agricultural lands, with expanding lifestyle farming and small-scale tourism (Scenic Rim Regional Council); a metropolitan area of high disadvantage and cultural diversity (Logan City Council); continuing to the urban coastal zone, Moreton Bay and islands (Redland City Council). This transect offered an opportunity to link risks and uncertainties across land and freshwater, coastal and marine environments and communities.

The idea was to develop and test a process for generating locally applicable knowledge to support climate change adaptation planning, and connect and inspire communities and their constituent groups to become involved. The process was called climate roundtables to promote an egalitarian mindset, and referred always to climate variability rather than change in order to avert divisive discussion on the reality or otherwise of human-induced climate change.

The environmental and social development staff of the three local governments were keen and assisted strongly in the planning, but opted to keep a low profile at the roundtables. One roundtable was held in each of the three local government areas (about 25 people at each), then a fourth to bring in people with a regional but not a local perspective: many of the local participants joined this too, making a large workshop of about 80 people. Participants were selected from a carefully researched profile of organizations and activities in each local area, leading to identification of a set of organizations, then individuals to attend, for each (8). Aboriginal Traditional Owners were invited to and attended each roundtable. Each event opened with a Traditional Owner welcome or acknowledgement, and an Aboriginal team member from the study was dedicated to their support. The research team consisted of social and physical scientists, expert facilitators (one with an agricultural and one with a community background) and an Aboriginal member, and each event had international students as volunteers to enhance a sense of cultural diversity.

Each roundtable took five hours (including meal breaks) in order to fit within a school day. The steps in the process were aligned with Tuckman’s stages of formation of new groups: forming, norming, storming, performing and adjourning (9).

The process, steps and principles behind the roundtable design are as follows.

Step 1. Introductions (forming, according to Tuckman’s stages of group development)

After a Traditional Owner welcome or acknowledgement, everyone goes outside for an energetic and amusing introduction process.

The forming step uses four principles.

- Recognize cultural norms and honour local leadership.
- Orient participants.
- Start forming relationships.
- Provide a fun, physically active introduction.

Step 2. Climate timeline (norming)

Participants sat in groups around tables and were asked to recall significant climatic events over their lifetime in the area where the roundtable was being held. After individual reflection, they shared within their small groups, and then each table reported findings to the larger group. These climatic events were recorded on a hand-drawn timeline on a whiteboard. The facilitator asked participants for any particular observations or trends they could identify.

This step uses two principles.

- Start eliciting and acknowledging participants' knowledge before any science presentations.
- Build confidence in their own knowledge and pleasure in sharing insights.

Step 3. Climate briefing (norming)

A presentation by a biophysical science team member outlined the latest climate projections for the region and defined key terms. The timing of this session was particularly important; it was held early in the day so as to provide information, but not so early that participants felt the event was science-led.

This step uses three principles.

- Some science briefing is necessary to even up levels of knowledge, explain necessary terminology and (for some) provide more information.
- Be informative but not too detailed.
- Present science information after participants have begun sharing their knowledge; try to present it as complementary to rather than superior or more informed than local knowledge.

Step 4. Brainstorm (norming to storming)

Participants brainstormed in groups around each table. They discussed their concerns, feelings, observations, and risks and opportunities around climate variability and change within and across the region. Maps were provided on the walls and tables for reference. A spokesperson from each group then reported key points to all participants.

Step 4 uses a single principle. Defuse passions by allowing people's key points to be heard and noted early. When they have had a chance to air their key points, they are more ready to listen to others.

Step 5. Systems analysis through influence diagrams (performing)

Participants self-selected into working groups of 5–6 people each to consider drought, heat, fire, floods, storms or sea level rise. Following a brief demonstration, the groups worked together to construct influence diagrams on large sticky curtains showing effects of their chosen climate variable on ecosystems, communities, families and individuals, livelihoods, infrastructure and the economy, and to show how these impacts connect through multiple pathways. When each diagram was complete, participants studied the other groups' diagrams to question and validate, and add new ideas or influences to them.

The performing step uses three principles.

- Elicit systems knowledge through an enjoyable, feasible process.
- Limit group sizes to 5–6 people.
- Provide for physical action.

Step 6. Key opportunities for adaptation (performing, looking towards adjourning)

Still in groups based on their chosen climate extremes, the participants returned to their tables and canvassed key concerns and priorities emerging from their influence diagrams. They recorded their priorities for action and reported these back to the larger group.

This step uses a single principle: communities seek outcomes, and do not welcome discussions that do not lead towards action.

Step 7. Close and evaluation (adjourning)

Participants were thanked, asked for final comments, told of the future steps for the project, and completed a one-page evaluation questionnaire. Those willing to be contacted again participated in an evaluation interview some six months later. Both evaluations showed very strong results in terms of enthusiasm for the process, increases in knowledge and awareness; sense of empowerment and increased networks (7).

The adjourning step uses two principles:

- Inform participants of future steps and expected outcomes.
- Evaluation is important.

Lessons learnt

From this research and on-the ground fieldwork experience in strengthening community resilience, a number of lessons can be distilled that might be helpful also to Europe. They are listed below not necessarily in a hierarchical order.

First, **seek diversity and engagement**. Community resilience-building exercises, where undertaken at all, are typically restricted to a particular sector, i.e. one government department, or collaborators with a shared interest, who will tend to recruit those they deem relevant to their topic. Thus, environmental community groups and farmers would be considered logical inclusions in a climate change engagement process, but artists, members of diverse religions, older people and culturally diverse residents of a district (e.g. South Sea Islanders in the South East Queensland urban location) would probably not. A community resilience approach should reflect the breadth of each community, not just the networks of the health or the environmental department if they are leading an intervention.

Second, **empowering approaches are needed**. While government departments, nongovernmental organizations and researchers can assist and even help mobilize resilience-building activity, focus should be on what communities and groups are doing themselves (with or without a little lift) and not on what these institutions are orchestrating and coordinating. A collaborative approach should be taken or a hands-off approach to allow the community to take charge as far as possible. The community works fairly, without exacerbating local inequalities. Some communities will need support and stimulation, as in any community-development approach.

Third, **think in terms of community development rather than community engagement**. Community-development approaches assist communities to strengthen themselves, according to their own criteria of what is important and valued, through processes that suit them and at their own pace. The process is often slow, because of the need for community members to own the process. Community engagement, by contrast, is a term favoured by external organizations, which can be tempted to think in terms of engaging communities in their agendas, rather than identifying with and supporting community agendas. No one can build resilience for a community; at most, they can help a community to build resilience themselves. Thus, community development should be a method of choice (10).

Fourth, **environment, financial and social aspects are intertwined in resilience**. In Stanthorpe, the environment is both a source of crises (fires and hailstorms), and a source of resilience in that it attracted a particular population, and enables many recovery options. The climate roundtable outputs in South East Queensland typically showed chains of influence from a climate variable (e.g. many more extreme heat days per year) to ecological, financial, lifestyle and thence psychological effects.

Fifth, **resilience is a multilevel phenomenon** (11). The Stanthorpe study shows that individual and community resilience can reinforce each other, and the Far North Queensland study shows that with some consciousness, regional organizations can be sensitive to, and help to build, resilience among the communities in the region. Conversely, organizations which are not careful could undermine community resilience. Adger et al. (12) found that in the climate change arena, some governments made policies and took actions that complemented and supported community initiatives, whereas others ignored and worked against community efforts, risking loss of community initiative and combined effectiveness.

Sixth, **for communities, resilience can be multifunctional**. In the ecology literature, there is an assumption that resilience is specific, that something must be resilient to specific types of shocks and stress. With communities, generalized resilience is much more possible. The same characteristics, sense of agency and self-organizing ability that allow communities to meet a natural disaster will also contribute to meeting economic crises, a new industry in their midst or population decline. Thus, supporting communities to build their resilience can be approached in an open-ended way. This is a further reason for including all types of members in any community, not limiting to those who are stakeholders towards specific threats. Building a community's strengths and potential for resilience brings multiple, long-term benefits.

Acknowledgements

The author wishes to thank the research team of Professor Desley Hegney, Dr Elizabeth Buikstra, Professor Peter Baker, Professor Cath Rogers-Clark, Dr Kath McLachlan, Dr Christine King, Professor Michael Cuthill, Dr Kirsten Maclean, Dr Bradd Witt and Distinguished Professor Emeritus Fikret Berkes on whose research this narrative is written.

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Canada. Public health approach to supporting resilience in Lac-Mégantic: the EnRiCH Framework

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Abstract

This two-part inspirational example from Quebec, Canada, provides an overview of the public health approach to supporting resilience as a healing process in a community traumatized by horrible accidents that caused human casualties, environmental contamination and a wide range of health and social problems. This first part shows that the actions undertaken to strengthen community resilience used what is now known as the EnRiCH Resilience Framework for High-Risk Populations. This Framework is applicable to communities in the recovery phase of a disaster. The actions implemented within the EnRiCH Framework take a whole-of-society approach to disaster risk reduction. This narrative highlights the usefulness of the EnRiCH Framework to strengthen resilience in communities. The second part, the last inspirational experience in this Compendium, narrates how Photovoice was used within the healing processes undertaken to support the population of Lac-Mégantic. The narrative used for the Canadian experience differs in format from the other inspirational examples in this Compendium in order to provide detailed information on the EnRiCH Framework that could be relevant to the European context.

Issue

Tranquillity is a defining feature of the town of Lac-Mégantic and the surrounding area of Le Granit, in Quebec, Canada. The beautiful lake, caring people and calmness offer a peaceful living environment and a welcome respite from the hustle and bustle of large city life.

That tranquility was interrupted on 6 July 2013 when tragedy struck the town. A train transporting 72 tank cars of oil rolled 7.2 miles down a hill at a speed of 65 mph, derailed and exploded (1). This event resulted in the death of 47 people and the decimation of many homes and the downtown core. It created an environmental disaster, as more than 6 million litres of oil spilled, much of which caught fire and burned or seeped into the soil deeply contaminating a large area; 100 000 litres of oil spilled into the lake and the river (2). This event carved a new trajectory for the town. It brought widespread awareness of the risks associated with ground transport of dangerous materials, especially in small rural towns in Canada.

While this rail accident is part of history, its legacy is a reality for many people in this town and the surrounding area of Le Granit. Some years have passed since this event, but additional stressors stemming from this tragedy have presented ongoing challenges, including the processes associated with decontamination, demolition and rebuilding the downtown core, and tensions surrounding the class-action lawsuits and re-introduction of rail transport through the town (3). Part of the challenge in supporting resilience in a disaster such as this, is the ongoing need to monitor and address short- and long-term psychosocial impacts while supporting the community in its efforts to move forward (3).

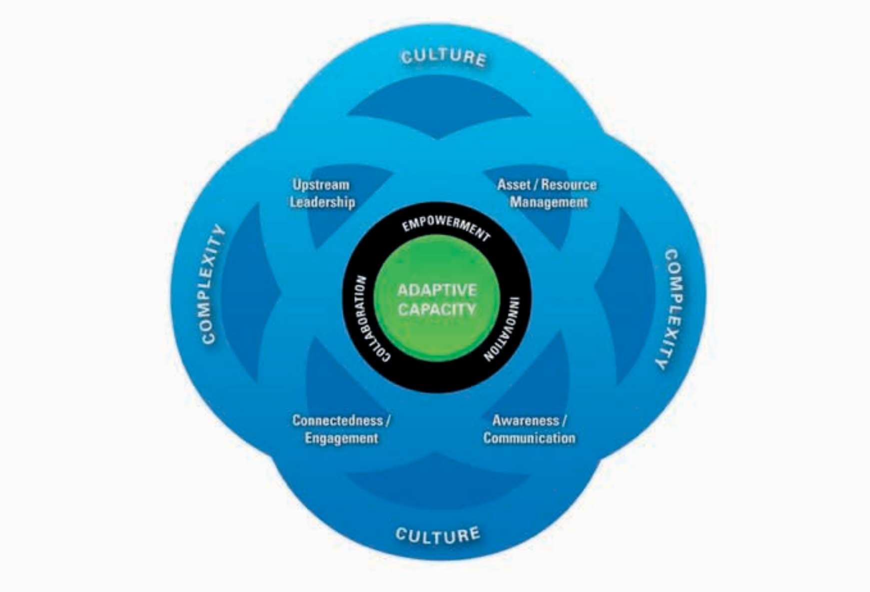
Resilience is a common word used in Lac-Mégantic. The people of this town understand well what it takes to bounce back – and then move forward – from an event like this (4). The path is complex, and at times bewildering. They have however persevered and have demonstrated resilience can emerge through collaboration, empowerment and innovation.

What follows is an overview of the public health approach to supporting resilience in Lac-Mégantic and the surrounding area of Le Granit, using elements of the EnRiCH Resilience Framework for High-Risk Populations (5). Though it was developed from a community-based research project focused on populations at heightened risk, the Framework is applicable to communities in the recovery phase of a disaster, given its emphasis on enhancing asset-profiles, as part of a whole-of-society approach to disaster risk reduction.

Action

Adaptive capacity is at the core of the EnRiCH Framework (Fig. 5.3) (5). The rationale is that resilience, while demonstrated after an adverse event, manifests from adaptive capacity (6,7). Macro-, meso- and micro-level activities focused on supporting adaptive capacity provide communities with the reserves to respond and recover following a disaster. While upstream preparedness focuses on building adaptive capacity, the same thing can be said about recovery efforts, which focus on bringing a community back to a state of optimal functioning (5).

Fig. 5.3 The EnRiCH Resilience Framework for High-Risk Populations



Source: reproduced with permission from the publisher of O'Sullivan et al. (5).

The three drivers of adaptive capacity identified in this Framework are empowerment, collaboration and innovation. Each driver can be leveraged across four strategic areas for intervention to support resilience: upstream leadership, connectedness/engagement, awareness/communication and asset/resource management (5). The remainder of this narrative provides examples of public health actions taken in response to the Lac-Mégantic tragedy that align with each element of this Framework, noting careful consideration of the local culture and complexity of short- and long-term impacts.

Upstream leadership

Leadership for the public health response and recovery from this event was spearheaded by the Public Health Branch of the Region of Estrie, which is the regional government for the eastern townships of Quebec, where Le Granit is situated. Extensive collaboration has taken place between the regional and local governments and stakeholders to ensure appropriate multilevel response to the event, and adaptation of support services to meet individual and community needs across the stages of recovery. After the initial emergency intervention phase, public health advocacy was important to assure and maintain long-term involvement to support the community.

An important aspect of upstream leadership has been the prioritization and investment in monitoring both positive and negative aspects of psychological health of the region across different stages of recovery, with particular emphasis on the area closest to the location of the disaster. The Estrie Public Health Survey has been administered annually since 2014, and has included the whole region to ensure appropriate comparison and understanding of the unique impacts of the people exposed to this event. The results of the Estrie Public Health Survey have been announced to the community first, respecting the importance of hearing the information directly from local leaders, before the widespread media coverage (3).

The results from the 2015 Estrie Public Health Survey, two years following initial tragedy, showed that despite strengths like a strong sense of belonging to local community and high levels of social support, a substantial proportion of the population in and around Lac-Mégantic has continued to experience symptoms of post-traumatic stress. This finding prompted a new course of action – with emphasis on community engagement and sustainable investment in social infrastructure (3).

The first step toward developing a public health action plan was to host a day of reflection, held in Lac-Mégantic on 18 March 2016. One of the outputs from this event was the creation of a shared vision for moving forward in recovery, which was developed by roughly 50 participants – representing stakeholders, decision-makers and citizens. This vision, with citizen engagement at the heart of the process, formed the basis of a four-component action plan, with the following objectives:

- empower community members;
- develop a positive presentation of the community;
- understand better the impacts of the tragedy on youth and put actions in place to support them; and
- increase the psychological well-being of the population.

The four axes of the public health action plan include:

1. establishment of a gathering place for the community to support connection and communication;
2. promotion of a positive campaign to share citizen visions for the community, including a Photovoice initiative where citizens would share their ideas and experiences through photography;

3. development of a child/youth psychological profile and expansion of the Estrie Public Health Survey to monitor the health of children and youth; and
4. recurrent investment through the creation of a permanent community outreach team (3).

An important attribute of this public health action plan is the high-level commitment by a wide range of community partners, which has been demonstrated through prioritization of capacity building and long-term investment. Supported by the Québec Ministry of Health and Social Services, to address the fourth axis of the action plan, the Public Health Branch of the Region of Estrie invested 250 000 Canadian dollars as a recurrent investment to create a permanent community outreach team in Lac-Mégantic (i.e. three health and social service professionals supported by the Public Health Branch and three supported by the Canadian Red Cross). This investment underscores leadership recognition of the importance of adapting to evolving needs through different stages of recovery.

The permanent outreach team is located in the downtown core in Lac-Mégantic, in a gathering place called La Gare, at the former train station. The team has a mandate of supporting community actions and providing psychosocial services to people in the community, in places outside a clinical setting. These services include daily interactions, as well as specific activities derived from the action plan; they focus on promoting health and well-being, and fostering community mobilization to move forward in rebuilding. In reality, the outreach team provides a link between public health, clinical psychosocial services, other community partners and the citizens of Lac-Mégantic and the surrounding area. The recurrent investment in this type of support demonstrates upstream leadership through recognition of the need for sustainable infrastructure with direct links to the community members to support long-term recovery and resilience.

From left, the Lac-Mégantic Community Outreach Team of Ms Catherine Bouffard (Health Promoting Agent); Ms Marie-Claude Maillet (Community Organizer); Ms Chantale Clusiault (Health Promoting Agent); Ms Geneviève Lalonde (Health Promoting Agent); Cindy Stewart (Outreach Worker); Ms Elise Nault-Horvath (Social Worker)

Connectedness/engagement

Consultation and engagement of citizens has been regarded as an important component by many partners in the community. Early on in the recovery phase, there was recognition of the need to share the story of Lac-Mégantic – before, during and after the tragedy – and to recognize the complexity of the grief experienced by individuals and the broader community.

Many activities were initiated in the year following the disaster, including an initiative led by the municipality, "Réinventer la ville" (reinvent the town) to involve citizens in the process of reconstruction and create a shared vision going forward. Over a 15-month period, there were many meetings where citizens contributed energy and ideas to the process of reconstruction. This level of engagement is unprecedented and underscores the commitment of the citizens to sharing their story and redefining their community to reflect the full context. In the health sector, a psychosocial recovery team was present in the community in the first recovery period. Members of this team listened to and supported citizens and groups participating in these initiatives.

During the day of reflection in March 2016, citizens and service providers expressed the need for connection and engagement; they emphasized the importance of dissociating the image of the tragedy from the identity of the community. The discussion highlighted how the tragedy had overshadowed the history of this town, and how the association between the name of the town and the disaster has been detrimental to recovery and restoring vitality in the community (8). Even today, several years after the disaster, a simple Google search with the words "Lac-Mégantic" shows images of the train explosion as the top stories. Residents from the town are inundated with questions from visitors about the disaster and its impacts, making it difficult for the community to live peacefully without constant reminders of the event.

The desire to dissociate the town image from the image of the disaster has been a continuous theme that has permeated the experience of the community following this tragedy, and community members frequently express this feeling as "we are more than the tragedy". This need has been documented in other communities who have been harmed by extreme adverse events and underscores the importance of engaging citizens and framing the image of recovering communities as more than their experience of disasters (9).

Asset/resource management

The allocation of resources across the different axes in the public health action plan for this community has prioritized investment in provision of support services for those who continue to experience symptoms of post-traumatic stress, and community activities to support the positive campaign to reinvent the town. An important aspect has been to invest in public spaces to facilitate positive social interactions.

One initiative within the second axis of the action plan is a Photovoice project which began in March 2017. The purpose was to engage citizens in a creative process of mapping the assets in the community using photography, and to create an opportunity for them to share experiences and their vision for their community. Following six months of active engagement in creating a gallery of photographs and accompanying narrative to tell their story of Lac-Mégantic, the Photovoice group hosted a vernissage and exposition in Lac-Mégantic in September 2017; the Federal Minister of Parliament for the Region of Mégantic–L'Érable, Mr Luc Berthold, hosted a second exposition in the Canadian Parliament buildings in Ottawa and invited all federal ministers and senators. These expositions provided an opportunity for the citizens who took part in the Photovoice initiative to discuss their experiences and ideas with decision-makers, and to inform future policy development and reform.

Photovoice (10) and asset mapping (11) are participatory approaches to citizen engagement that have been used broadly to elicit social change and support community development. The Lac-Mégantic Photovoice initiative is described in the next inspirational example in more detail to highlight the importance of creating opportunities for citizen engagement and the benefits of community asset mapping to support resilience.

Awareness/communication

Situational awareness and effective communication are critical elements which contribute to resilience (5,7). The validity of this statement has been experienced time and again surrounding the Lac-Mégantic tragedy. The need for transparent, accurate, empathic, risk communication has been paramount throughout the response and recovery phases where there was a need to explain the environmental impacts of the oil spill, and the actions implemented to address the risks and impacts. Each aspect of the public health action plan takes into account the need to support awareness and communication at all levels.

Prior to the day of reflection and creation of the public health action plan, one activity that was undertaken to support the resilience of this community was a collaborative book, which was published in French in November 2016. The book, edited by Dr Danielle Maltais and Mrs Céline Larin, is titled *Lac-Mégantic: De la tragédie… à la resilience* (4). It provides a comprehensive account of the experience of this disaster and details different activities (within and beyond the public health domain) that have contributed to the resilience of this community.

Effective communication has been a priority within the different activities led by the public health team. For example, the leadership recognized the importance of doing a press release focused on the local community first, prior to releasing the information from the Estrie Public Health Survey more broadly. The outreach team, located in a central gathering place in the community, is situated to reach the community, not only to provide services outside the clinical setting, but also to ensure they are connected to the citizens where they are (axis 1). The child/youth psychological profile (axis 3) is under development in collaboration with youth in the Lac-Mégantic community and the outreach team. The essence of the Photovoice initiative (axis 2) is to provide an opportunity for citizens to be agents of change.

Concluding remarks

In closing, the Lac-Mégantic train derailment and explosion is described as one of the worst rail disasters in Canada (3). It highlighted the risk within the transportation sector, as well as the importance of public health preparedness, response and recovery efforts. This experience has also provided an opportunity to understand how resilience can manifest from, and despite, a tragedy like this. The commitment to upstream leadership (including shared vision and sustainable investment), coupled with community engagement, asset management and effective communication, have contributed to collaboration, empowerment and innovation in this region; and ultimately resilience across the different stages of recovery. The community has actively reclaimed its tranquillity and is sharing this vision and its experience of recovery with others. It is an inspiring example of resilience and a whole-of-society approach to disaster recovery.

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Canada. Public health approach to supporting resilience in Lac-Mégantic: Photovoice

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Background

As the town of Lac-Mégantic, in the eastern townships of Quebec, Canada, marked the fourth anniversary of the train explosion and environmental disaster that decimated the downtown core, 13 citizens were actively engaged in planning a Photovoice exhibition to share their reflections on the recovery process and their vision for the community looking forward to 2025. The exhibition was titled "Between Memory and Hope: Turbulence, Resilience, and Revival".

The exhibition was an important part of an intensive participatory action research project which spanned eight months. The project, which began in January 2017, was a collaborative initiative between citizens, the public health outreach team and a research team from the University of Ottawa, Canada. It was funded by the Department of Public Health for the Region of Estrie, through funding made available by the Québec Ministry of Health and Social Services. This project aligned with the second axis of the public health action plan to support post-disaster recovery: promotion of a positive campaign to share citizen visions for the community, including a Photovoice initiative where citizens would share their ideas and experiences through photography (1).

The role of a positive approach in post-disaster recovery

For communities experiencing disaster, hope and citizen engagement are important elements in recovery (2,3). While hope provides some semblance of relief and direction in the recovery process, citizen engagement is a way to contribute to the community and regain a sense of control and influence over the social and physical environments.

As described in the previous inspirational example, discussion at the day of reflection in Lac-Mégantic emphasized the need for a positive approach to dissociate the image of the disaster from this community. Photovoice, developed by Wang & Burris (4), was suggested as a participatory approach that could provide an opportunity for citizen engagement in the positive campaign for the community, create space for citizen voices to be heard and contribute knowledge on the use of asset-based approaches in post-disaster recovery.

With these outcomes in mind, the Lac-Mégantic Photovoice initiative was created. Its overarching purpose was to *give power to the voices of the people in the Lac-Mégantic community to express their vision of a positive public relations campaign and their experiences with how this strategy supports long-term community recovery and resilience following disaster*.

Photovoice initiative in Lac-Mégantic

Photovoice is an action research method designed to engage citizens as co-researchers on a topic that is important to them in their community (4). The intention is to create positive social change by providing citizens with an opportunity to share their experiences, concerns and ideas through photographs and narratives (5). Participants are given cameras and asked to take pictures that represent their ideas and feelings about a given topic. They bring the pictures back to the Lac-Mégantic Photovoice Group to explain how the images respond to the research topic, and the images are used to guide the discussion about important social issues.

A photo exhibition is typically hosted at the end of a Photovoice project, where decision-makers and other community members are invited to hear the participant messages related to the research topic. The photo exhibition, with the presentation of the photo images and narratives, creates a space for dialogue and influence that is important for authentic citizen engagement (6). In post-disaster recovery, creation of this type of space acknowledges the need for citizens to have a voice and some influence on the decisions that impact their living environment.

The protocol for the Photovoice project was reviewed by the ethics review board of the University of Ottawa; following its approval, citizens from Lac-Mégantic and the surrounding area in Le Granit were invited to participate in the project. A total of 19 participants were recruited, and over the course of the project 13 people (2 men, 11 women) continued to be part of the citizen-based Lac-Mégantic Photovoice Group, which ranged in age from 18 to 81 years.

Three Photovoice groups were formed to accommodate scheduling and keep the group sizes between two and eight people. Each month, the participants decided on a photo assignment for their group, took photos, and brought them back for discussion. Specifically, the participants were asked to create photo assignments to help with the following tasks.

- Explain what makes Lac-Mégantic an attractive place to call home.
- Identify assets that support resilience.
- Describe their vision of the community and what it will look and feel like by 2025.
- Create a digital gallery of photographs and narratives to describe how the positive public relations campaign has impacted resilience in this community.

Each Photovoice session was audio-recorded and transcribed by the research team. Preliminary analysis of themes was conducted and brought back to the groups for confirmation and further discussion. A total of 108 pictures were taken and discussed by the participants.

The Lac-Mégantic Photovoice exhibitions

This section highlights the main themes, and provides sample photos and accompanying narratives describing what the Photovoice participants believe make Lac-Mégantic an attractive place to call home, and the assets that contribute to its resilience. The Lac-Mégantic Photovoice Group chose the themes and narratives highlighted in Table 5.1 for display at the exhibitions. They represent a small selection of the 108 photos that provided the structure for the group discussions and informed the messaging for decision-makers and other audiences.

Table 5.1. Main themes with examples of photos and extracts of text chosen by the Photovoice participants to convey each theme

Theme	Description	Photo which conveys the theme	Translated text from the Photovoice discussions
Resilience and quality of life	Emphasizes resilience in the face of disaster, reclaiming the tranquillity and quality of life the community provides	 © Lac-Mégantic Photovoice Project	In this photo …, I find that we feel the protection when we can see him by the lake and he is providing protection. We can say he is "the protector". On the lantern there are 47 stars which represent the 47 victims of the tragedy. It can also be interpreted how the statue guides them toward the light or toward the lake.
Richness of the region	Highlights the natural assets of being close to nature, particularly the lake, mountains and wildlife	 © Lac-Mégantic Photovoice Project	This represents the beauty of Lac-Mégantic … being close to nature, because the deer is in the heart of the town.
Culture and heritage	Reflects on the culture of the small town and surrounding area, the participants' heritage, and how this background has not only contributed to resilience but also shaped their community in the past and can be reshaped to what they envision for the future	 © Lac-Mégantic Photovoice Project	The bandstand/gazebo ... is a witness of what happened, that remained following the 2013 tragedy ….It is a gathering point, for comfort and enjoyment of festivities. If we look closely we can see the lake and the mountain. In a way, all the surrounding region has been touched by what happened to Lac-Mégantic.
Contrasts of the city	Focuses on the different perspectives that can be brought to any building project, any issue the community faces	 © Lac-Mégantic Photovoice Project	The child focuses his gaze on what surrounds him, and he can act and walk confidently toward a future that is currently being constructed. There is still much work to do, to reflect, on how precious and enriching it is to be attentive to different points of view within the rebuilding projects… Even if the process is long, sometimes painful.
People who made a difference	Emphasizes the need for people to realize that they can make a difference in their own life and the lives of others	 © Lac-Mégantic Photovoice Proje	[The message on the blackboard behind the Spinning Bikes is a reminder to] … make a difference in your life and in the lives of others around you.

Table 5.1. (contd)

Theme	Description	Photo which conveys the theme	Translated text from the Photovoice discussions
Vision of the city in 2025	Underscores assets that contribute to positive health, ensuring the natural assets of the region can be enjoyed by all; and emphasizes ecological strategies to protect the environment and conscious development that considers the well-being and enjoyment of the whole population	 © Lac-Mégantic Photovoice Project	This photo illustrates being mindful of environmental issues in terms of transportation that is ecological… I wish for a town that is ecological in 2025. My second wish is concerning the greenspace in the background … I would like for that space to be developed to serve the whole population, by preserving the breathtaking view.

After five months, the citizens who were part of the Lac-Mégantic Photovoice Group began planning the Photovoice exhibition with the public health outreach team. Four planning meetings took place with many hours of work in between to select the photos and create the narratives to accompany each photo. The Photovoice exhibition comprises 16 display boards.

The Lac-Mégantic Photovoice Group decided to include a slideshow to highlight all the photos that were discussed in the sessions – the photos that make up the gallery. A select number of photos in the slideshow were also accompanied by audio recordings prepared by the participants. One of the participants described the recordings as a way to emphasize the voice in Photovoice.

Participants generated a list of people and decision-makers they wanted to invite to the exhibition and created the invitation letter. The Lac-Mégantic Photovoice Group nominated several participants to prepare and give speeches and a presentation for the vernissage at an international meeting in Ottawa.

To date, the Lac-Mégantic Photovoice Group has hosted two Photovoice exhibitions and presented at an international workshop in Ottawa. The first exposition was in Lac-Mégantic, Québec, on 22–24 September 2017, and was held in a gathering place in the centre of town called La Gare, which is the former train station. Participants hosted a vernissage on the first night of the exhibition, before it was open to the public throughout the weekend. Many municipal delegates, including the director of public health and several community organization leaders attended the exhibition; this is in line with the intention of Photovoice: to create an opportunity for citizens engaged in the project to present their reflections and ideas directly to people in decision-making roles. Throughout the weekend, approximately 200 people (local citizens and visitors) attended the event, which was highlighted by the local newspaper on the front page of its weekly publication.

The second exposition was in Ottawa, (the capital city of Canada) where the federal government is predominantly located. Five representatives from the Lac-Mégantic Photovoice Group travelled 5.5 hours by car to Ottawa to present the Photovoice exhibition in the main Parliament building. The Federal Minister of Parliament for the Region of Mégantic–L'Érable, Mr Luc Berthold, and his team arranged the event. All senators, federal ministers and deputy ministers were invited. Approximately 30 members of Parliament attended including the Prime

Minister of Canada, Mr Justin Trudeau, the Federal Minister of Parliament for the Region of Mégantic–L'Érable, Mr Luc Berthold, and members of the Lac-Mégantic Photovoice Group, the public health outreach team and the University of Ottawa research team.


© Lac-Mégantic Photovoice Project

The Lac-Mégantic Photovoice exhibition in Ottawa in September 2017.

Lessons learnt

The different processes and impacts of the Photovoice initiative are under evaluation. The participants in the Lac-Mégantic Photovoice Group have completed two phone interviews – the first after the second Photovoice session and the second after the expositions. A survey was distributed to people who attended the exposition in Lac-Mégantic. The details of the evaluation will be published to share lessons learnt from this project and to benefit other communities who would like to implement this type of strategy.

For a community recovering from a disaster, the provision of time and space for citizens to talk about their experiences, the issues facing their community and the assets that support their resilience is a powerful engagement opportunity. It supports feelings of hope and empowers people to engage in dialogue about their community. Photovoice is a method that provides that opportunity; it is much more than taking pictures and talking about them. It is a catalyst that can spark energy in a group that wants to do something to create change in its community.

A key ingredient for the success of the project in Lac-Mégantic has been the energy of the citizens who devoted time and ideas to this initiative. In addition, this type of initiative cannot be implemented without leaders, within the community and beyond, who are willing to listen and be influenced by the voices of citizens who have experience before, during and after a disaster. Lac-Mégantic is more than the tragedy. It has a story that began long before the explosion, and a joie de vivre that will continue into the future. The engagement of citizens and leaders in developing the vision for the future is essential for long-term resilience after a disaster.

Acknowledgements

So many people have contributed to the ideas behind this project and to making it happen. The authors would like to thank the community of Lac-Mégantic for its inspiration and energy in supporting this work, Mr Yan Quirion for his efforts to raise awareness about the project and

Dr Mélissa Généreux who championed this initiative from the start and secured the funding to make it happen. Thank you to Ms Renelle Short, Ms Vanessa Bournival, Ms Camille Mageau, and Ms Emily Guy at the University of Ottawa for their tireless energy devoted to completing the transcriptions. Special thanks go to Ms Isabelle Laplante and Mr Luc Berthold for recognizing the importance of this project and creating the opportunity to host an exposition at Parliament.

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Part 6. Conclusions and way forward

This Compendium should be read together with two other publications on resilience published by the WHO Regional Office for Europe in 2017 (1,2). *Building resilience: a key pillar of Health 2020 and the Sustainable Development Goals* (1) reviews the scientific background for the inclusion of strengthening resilience into Health 2020. It outlines the importance of three levels of resilience: individual, community and system. It provides three analyses of on-the-ground action that strengthens these levels of resilience from three countries – Iceland, Malta and San Marino – who are members of the WHO Small Countries Initiative (1).

Strengthening resilience: a priority shared by Health 2020 and the Sustainable Development Goals (2) describes the synergy between the European framework for health and the SDGs. It outlines the key role resilience plays in basically all the SDGs (3). Indeed, much of this synergy finds its common ground on the very notion of resilience. Resilience – as advocated by both Health 2020 and the SDGs – requires healthy and robust citizens and communities. It also requires systems that can adequately handle potential vulnerabilities, shocks and disturbances by developing *adaptive*, *absorptive* and *anticipatory capacities*. Progress towards both the SDGs and Health 2020 also requires a proactive approach to resilience strengthening, usually referred to as *transformative capacity*. *Strengthening resilience: a priority shared by Health 2020 and the Sustainable Development Goals* (2) summarizes these capacities and the most frequently asked questions about resilience in two annexes. This Compendium revisited and expanded on those annexes by incorporating information from the lessons learnt in the inspirational examples (see Annexes 1 and 2).

To take into account the material in this Compendium and in the two other WHO publications mentioned above, the concluding remarks on the relevance of strengthening resilience within the conceptual frameworks of both Health 2020 and the SDGs are structured at three levels: scientific, strategic and operational. It is anticipated that the need for scientific evidence, know-how and practical examples of strengthening resilience will be in greater demand in the years to come. Creating a body of literature on resilience strengthening will be a crucial resource for countries to make progress towards achieving the SDGs. Such literature should expand the scientific backing of the role of strengthening resilience to bring about population health and well-being outcomes. It should also expand the know-how regarding how to strengthen individual, community and system resilience. It is hoped that this Compendium is one step forward in this direction.

Scientific considerations

The above-mentioned WHO publications review various health-related definitions of resilience by analysing the scientific literature. It was concluded that notwithstanding their differences, these definitions all point to the fact that resilience is connected to processes and skills that result in good individual and community health outcomes in spite of negative events, serious threats and hazards. These WHO publications point out that this definition has been broadened to include the resilience of social systems, including the health system and public health.

From an analysis of the literature, individual-level resilience can be referred to as the process of adapting well in the face of adversity, trauma, tragedy and threats. It also includes coping with significant stress caused by problematic and toxic relationships in the family or the workplace and bouncing back from difficult experiences. Similarly, community resilience is seen as the ability of social groups to withstand and recover from unfavourable circumstances. In the literature, community resilience is usually associated with social relationships and the activation of local resources that enable communities to cope with and counteract unhealthy stressors. Community assets such as the level of internal solidarity and mutual trust and the quality of social networks have proven to be protective and promoting factors to health and well-being and are clearly linked to resilience (1,2). System-level resilience is a key priority of the SDGs. It is defined as a system's capacity to absorb, adapt, anticipate and transform when exposed to external threats – or forecast shocks that bring about new challenges and opportunities – and still retain control over its remit and pursuit of its primary objectives and functions (2,3).

Thus, the scientific literature on resilience points to processes, resources and skills that have a positive effect on health and well-being outcomes, even in the face of negative events, such as serious threats and hazards. A better appreciation of the role of resilience might be achieved if elements – such as social capital, social relations and networks, community-supportive resources and other resilience-related factors – were explored and incorporated into the design and delivery of public health action. In this perspective, as indicated by the testimonial of Professor Sir Harry Burns in Part 1, creating conditions that enable people to gain control over their lives and destinies is a credible way to strengthen resilience and create environments that are supportive of health and well-being.

To sum up, the analyses behind this Compendium and the other two WHO publications provide evidence that population health and well-being require strengthening resilience at three levels: individual, community and system/society. Four resilience capacities, associated with these levels, are reported in the scientific literature: adaptive, absorptive, anticipatory and transformative. Annex 1 synthesizes the basic elements of these capacities.

Strategic considerations

Population health can be seen as a precondition for, an indicator and outcome of sustainable development. Building resilience and environments supportive of population health and well-being is instrumental in achieving all of the SDGs. It is not surprising therefore that strengthening resilience is a key strategic element for progress in both Health 2020 and the SDGs. As for the SDGs, system-level resilience and transformative resilience capacity are areas of particular strategic importance.

Using a so-called *resilience lens* to evaluate any action carried out by the health sector, as well as all the policy domains covered by the SDGs, is recommended based on the amount of evidence collected in this Compendium and the other two WHO publications on this subject. Given the structure and rationale of the SDGs, making the mutually reinforcing link among sustainable development, population health and resilience more visible would strongly enhance the position of public health within the 2030 Agenda for Sustainable Development (3).

Operational considerations

As far as the health policy sector is concerned, perhaps the most important implication of resilience is the potential role of health services and public health programmes in increasing people's control over their lives and destinies. This is key not only to promote health, but also to strengthen prevention, rehabilitation and healing processes. These are all areas in which the health sector has a clear role to perform. Supportive measures to strengthen individual and community resilience can be introduced even in the face of extreme situations, involving disease or natural disasters, as highlighted by some of the inspirational examples in this Compendium.

In public health, and in all services delivered by the health sectors, it is recommended that a *resilience-strengthening function* be built into the way in which programmes and services are designed and delivered. This is the kind of innovation that lies behind the rationale of including resilience strengthening within the Health 2020 framework. A built-in resilience-strengthening function in public health programmes and services that impact on population health and well-being would help to overcome fragmentation of action and maximize collaboration between institutions and civil–society organizations. Many of the examples in the Compendium highlight this.

References

1. Building resilience: a key pillar of Health 2020 and the Sustainable Development Goals – Examples from the WHO Small Countries Initiative. Copenhagen: WHO Regional Office for Europe; 2017 (http://www.euro.who.int/en/publications/abstracts/building-resilience-a-key-pillar-of-health-2020-and-the-sustainable-development-goals-examples-from-the-who-small-countries-initiative-2017, accessed 14 May 2018).
2. Strengthening resilience: a priority shared by Health 2020 and the Sustainable Development Goals. Copenhagen: WHO Regional Office for Europe; 2017 (http://www.euro.who.int/en/countries/monaco/publications/strengthening-resilience-a-priority-shared-by-health-2020-and-the-sustainable-development-goals-2017, accessed 14 May 2018).
3. Transforming our world: the 2030 Agenda for Sustainable Development. New York: United Nations; 2015.

Annex 1. Inspirational examples by type of resilience capacity

Type of capacity	Description	Inspirational examples
Adaptive	The ability of individuals, communities and systems to adjust to disturbances, hazards and shocks	All the inspirational examples in the Compendium show different aspects of adaptive capacity.
Absorptive	The ability to absorb and effectively cope with disturbances and shocks; the capacity to manage and recover from adverse conditions, using available skills, assets and resources.	Some inspirational examples incorporate substantial elements of absorptive capacity such as those from Austria, Bulgaria, Canada, Denmark, Kyrgyzstan and Spain. Two examples from the United Kingdom (Sheffield and the district of Blackburn with Darwen) offer many insights into the use of local skills and assets to strengthen community resilience. Furthermore, the lessons summarized in the narrative from Australia add relevant conceptual refinements and tools related to this capacity. Another example is the case study of San Marino described in a 2017 WHO publication (1).
Anticipatory	The ability to predict and reduce disturbances and risks by means of proactive action to minimize vulnerability.	The narratives from the Republic of Moldova and the former Yugoslav Republic of Macedonia are good examples of using anticipatory capacity. The case study of Malta is an excellent example of system-level resilience (1).
Transformative	This capacity applies mainly to systems. It refers to the ability of systems to transform their structures and means of operating to better address change and uncertainty. It is the ability to develop (new) systems that are more suited to new conditions. This capacity is very important when, for example, ecological, economic, technological, cultural or demographic changes render the existing policies and practices obsolete or untenable.	The inspirational examples from Finland, Italy, the Russian Federation and the United Kingdom (both North West England and Wales) have important characteristics of transformative capacity. Another example of this capacity is the case study of Iceland (1).

Source: adapted from the WHO Regional Office for Europe (1).

References

1. Building resilience: a key pillar of Health 2020 and the Sustainable Development Goals – Examples from the WHO Small Countries Initiative. Copenhagen: WHO Regional Office for Europe; 2017 (http://www.euro.who.int/en/publications/abstracts/building-resilience-a-key-pillar-of-health-2020-and-the-sustainable-development-goals-examples-from-the-who-small-countries-initiative-2017,accessed 14 May 2018).

Annex 2. Frequently asked questions about resilience, Health 2020 and the SDGs

Question	Answer
What is meant by resilience?	Traditionally, resilience has been related to processes and skills that result in good individual and community health outcomes in spite of negative events, serious threats and hazards. Strengthening resilience is a key element in both Health 2020 and the SDGs.
Are there different levels of resilience?	Yes, the body of literature describes resilience using three levels: individual, community and system.
How is resilience approached in Health 2020?	Health 2020 states that building resilience is a key factor in protecting and promoting population health and well-being. Collaboration among policy sectors and the full engagement of civil society are key elements for resilience building and developing supportive environments for health and well-being.
Why is resilience important for public health?	Resilience is important because it is a key factor in protecting and promoting health and well-being at the individual, community and system (or societal) levels.
Is resilience important in the SDGs?	Strengthening resilience is recommended in basically all actions related to the SDGs. Resilience is a key factor in the SDGs and a central mechanism for making progress in pursuing the 2030 Agenda for Sustainable Development (2).
Is the creation of supportive environments instrumental for strengthening and nurturing resilience?	The development of supportive environments is instrumental in building resilience. Resilience should always be seen in relation to the availability of such environments. Supportive environments include health-protective and -promoting resources in both the social and physical settings in which people are born, grow and age. They also include cultural, economic and political resources necessary for the health and well-being of the population.
Do factors that strengthen individual and community resilience change over the life-course?	Yes, they do. Factors that promote and protect resilience unfold over the life-course. Resilience-building mechanisms can vary, depending on life stages and situations. For example, there is evidence to show that in childhood and adolescence, family-related processes determine resilience to a large degree. In adulthood and later life, it may be affected by entrenched patterns of coping acquired over time, physiological stress responses and social relationships.
What main scientific concepts are related to resilience?	The field of study known as *salutogenesis* is very much linked to resilience. Studies in this area aim to explain why, in the face of adverse life circumstances, some people cope remarkably well, while others fail and develop pathogenic outcomes. Another concept is *social capital*, broadly defined as community resources that help create trust, solidarity and resilient social organizations. The *notion of control* is also important for resilience building. Creating conditions that enable people to gain control over their lives and destinies is essential in interventions that aim to strengthen resilience.
Do health systems and public health programmes have a role in strengthening and nurturing resilience?	Strengthening resilience forms part of effective practices in curative, rehabilitative, preventive and health-promotive actions undertaken by the health system and public health programmes. Augmenting people's control over their lives and destinies is perhaps the most important impact that health systems and public health can have in strengthening resilience. This is crucial for effective prevention, rehabilitation and healing processes.
Is resilience important in other policy sectors beyond health?	Resilience frameworks are important and increasingly used in various policy sectors, particularly in the domains of environment, climate change, energy, ecology, urban planning, social and economic development, agriculture and poverty reduction.

Source: adapted from the WHO Regional Office for Europe (1).

References

1. Strengthening resilience: a priority shared by Health 2020 and the Sustainable Development Goals. Copenhagen: WHO Regional Office for Europe; 2017 (http://www.euro.who.int/en/countries/monaco/publications/strengthening-resilience-a-priority-shared-by-health-2020-and-the-sustainable-development-goals-2017, accessed 14 May 2018).
2. Transforming our world: the 2030 Agenda for Sustainable Development. New York: United Nations; 2015.

The WHO Regional Office for Europe

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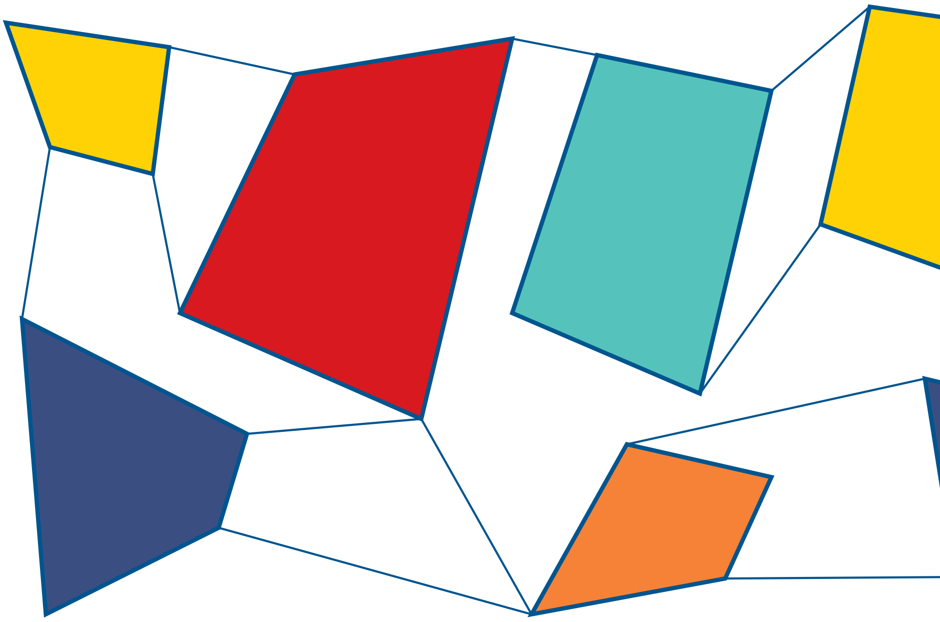

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ISBN 9789289053235
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