
The Creating Health Collaborative

A REPORT FROM THE COLLABORATIVE'S FIRST MEETING ON JULY 22ND, 2014
REPORT DATE: NOVEMBER 10TH, 2014



Contents

Summary.....	2
Introduction.....	3
What is ‘creating health’?.....	5
What is preventing us creating health?.....	7
Examples that we’ve already started.....	10
The emerging principles for creating health	11
Things we need to work out to make creating health the norm	13
Appendix A: The creating health collaborative.....	15
Appendix B: Words.....	16

The Creating Health Collaborative is an international group aiming to illustrate health beyond the bio-medical model by sharing individual initiatives in order to receive feedback and seed debate. Part of its work includes furthering the field of evaluating community-defined interventions. Although there are numerous initiatives trying to find new ways to meet the growing demand for care few openly embrace the idea of health beyond the bio-medical model, fewer focus on communities as the definers and solvers of their own challenges, there is almost no discussion of new evaluative techniques, and none tie these together with the need for new approaches to evaluation.

Learn more at www.pstamber.com/exploring/

Summary



We are struggling to meet the growing demand for care and yet it will only grow.

At the heart of this struggle is our inability to define health as more than just the absence of disease. Broader definitions of health may enable us to *create* health and so offset the growing demand for care.

The Creating Health Collaborative was formed to understand why, despite their potential, broader definitions of health remain only a fringe of health innovation.

The broad concepts that underpin the idea of creating health are: letting people decide what health means to them, which is often about living fulfilling lives rather than health *per se*; not being didactic about *who* creates health; accepting that all definitions will be local and hence plurality will be the norm; embracing 'complexity'; and, given that this is largely uncharted territory, learning by doing.

We are prevented from *creating* health by talking about it from the lens of health care, which is actually organised around the bio-medical model – responding when someone is sick. When we try to think afresh, we're more tethered to the bio-medical model than we realise, especially in terms of evaluation. There are too many theories on how to create health, leading to 'analysis paralysis', and as a result, we continue to have blind faith in Band Aids, such as safety net programmes. We over-value formal expertise, accumulated through academia, failing to acknowledge local heuristics, and often make the issue too big by making it about poverty and inequality.

The emerging principles for creating health appear to be letting people define health, embracing complexity including being open to unintended consequences, running creating health projects for at least five years, giving community control, focussing on value before considering metrics, always operating at the individual and community level, meticulously recording processes, accepting failure while looking to fail fast, building a resilient team, and embracing the notion of group attribution.

The Collaborative was unanimous that the only way to learn about creating health was to try it. Things we need to learn include: communicating the trade-off between health and well-being; finding catalytic capital that 'gets it'; rewarding better processes, even if outcomes are equivocal; how to surface and invest in the 'scaffold' that connects communities; the idea of collective attribution; and how to build a community of practice that will learn from one another.

The Collaborative is currently seeking funding to continue its work.

Introduction

We are struggling to meet the growing demand for care.

And yet with ageing populations, the rise of lifestyle-related chronic conditions, and more diagnoses as a result of biological discovery, the demand for care will only grow.

At the heart of our struggle is our inability to define health as more than just the absence of disease – a definition derived from the bio-medical model, which sees people as individuals and suggests responding when they're sick or likely to become sick.

Broader definitions of health may enable us to *create* health and so offset the growing demand for care.

Some of our responses are, in fact, already embracing broader definitions, such as social connectivity and food sovereignty. Despite their potential, however, such initiatives remain only a fringe of health innovation.

The 'Creating Health Incubation Group' was formed to understand why.

Seeing health only through the eyes of health care is especially problematic given that it is increasingly recognised that the profession and industry contributes only 10-20% of what we call health, the rest comes from our genes, behaviours, social factors and the environment.

Embracing broader definitions of health implicitly means asking people and communities what health means to them. This brings with it plurality and, given that our social contexts are always changing, constant evolution.

The idea of creating health, then, has to operate within a complex environment.

The 'Creating Health Incubation Group' met for the first time by teleconference on June 11th, 2014, and then face-to-face July 22nd, 2014. This is the report of the face-to-face meeting.

The aims of the meeting were:

1. *To build relationships between the members of the Group*
2. *To share our work in order to identify common struggles*
3. *To understand the resources and capacity available at each organisation*
4. *To develop a sense of what we might do together and how it would be different to what else is out there*
5. *And to start questioning the language that we use in health to see if a different vocabulary might create opportunities*

The Group adopted the following principles:

1. *We will be open to new ideas about – and definitions of – health*
2. *We will learn by doing or by what has been done (concrete examples)*
3. *We will focus on practical ways to change*
4. *We will share the leadership of the Group*
5. *We will openly hold each other to account on the above principles*

During the day we shared our struggles, found common ground, discussed the challenges of evaluation in creating health, talked about what we'd rather be doing if we didn't have to operate within the bio-medical model, looked at some of the emerging ideas to create the business case for using broader definitions of health, and then discussed what we, as a group, might do going forwards.

This report is not a session-by-session description of the meeting but an overview of five themes that surfaced in the discussions:

1. *What is 'creating health'?*
2. *What is preventing us creating health?*
3. *Examples illustrating that we've already started*
4. *The emerging principles for creating health*
5. *Things we need to work out to make creating health the norm?*

The members of the Group that attended the July 22nd meeting are included in *Appendix A*. All attendees have approved the content of this report.

During the meeting the Group members were encouraged to write down words and phrases that they considered helpful, unhelpful and/or ambiguous. They are included in this report as *Appendix B*.

Since July 22nd the Group has contributed to the planning of a meeting held by the Institute of Medicine on designing evaluations for what communities really value and submitted a request for funding to a number of funders.

As a by-product of the activities since the meeting the Group has agreed to rename itself the 'Creating Health Collaborative', which is why the latter name is in the header of this document and throughout the reporting.

What is ‘creating health’?

By discussing current projects, the Collaborative surfaced and debated how they were thinking about health beyond the bio-medical model.



What follows is what the Collaborative believes to be the broad concepts that underpin the idea of creating health.

Health is what people want it to be

Most people don't want health, *per se*.

They want to live fulfilling lives and they want their health to facilitate that. From this lens it's easy to see that health is not just bio-medical. It includes things like:

- *Physical functioning*
- *Financial security*
- *Fulfilment from daily activities*
- *Emotional security*
- *Nourishing relationships with family and friends*
- *A sense of community*
- *Meaning*

A catchall term for this broader definition of health is “well-being”, although there are many synonyms and definitions, including the idea of “life satisfaction”.

From a bio-medical perspective, these broader definitions of health are nebulous, perhaps even problematic. However, it's essential that we start from here.

An important part of health being what people want it to be is people being able to speak for themselves. All too often we rely on well-meaning intermediaries, such as academics or ‘community activists’, to be the voice of communities. To create health we have to truly understand what people want – in their *own* words.

Who does the creating is not fixed

There is no creating health sector.

There is an assumption that the health care sector should be charged with creating health but the health care sector is actually a sick care sector – it is about responding when people are sick or likely to become sick – and hence is not geared towards *creating* health.

There is significant opportunity to create new players to meet the need to create health.

Given that many aspects of health have a social element, it's likely that new players will be community based organisations or perhaps even informal groups within communities. This has the potential to challenge the current assumption that health is something that has to be provided by outside expertise. This assumption has rendered people and communities into the role of recipient or beneficiary, grateful for whatever is provided.

Creating health, then, has the potential to shift the locus of control away from the health care sector and into communities. This also has the potential to see communities for what they have – and hence can leverage to create health – rather than what they do not have – a judgement often made by outside experts.

Plurality means it's always local

Different communities will define health differently, although some overlap is likely. Creating health embraces this plurality and accepts that no two interventions will be *exactly* the same because no two communities are *exactly* the same.

Part of this includes respecting local expertise as being on a par with formal expertise. This parity establishes mutual respect, ensures a local 'system' does not supersede the local community, and reinforces the idea that all communities have assets that can be leveraged.

The real world is complex

Communities are dynamic and we must learn to work with constant change.

Embracing this 'complexity' means abandoning bio-medical notions of causality (and hence attribution). It also means understanding communities as networks, such that all interventions should work at both the individual and the community level. Doing this means understanding the interconnectedness of a community, akin to a scaffold that holds the community together.

It's action, not words

Finally, creating health has to be about trying.

This is uncharted territory. We don't yet understand the methodologies of engagement, the types of interventions to try, or even the approach to evaluation. We'll only learn this by doing. Creating health has to be action-oriented.

What is preventing us creating health?

Despite general acceptance of the need to think more broadly about health, the Collaborative discussed what they believe is holding people back

What follows is an amalgamation of what the Collaborative felt is preventing us from trying to create health.

We're starting in the wrong place

When we talk about health we usually do so from the lens of health care.

We have to remember that health care is actually *sick* care – responding when someone has a biological deficit (for which they get care) or a risk of acquiring one (for which they get prevention). This is not *creating* health.

Despite all this, health care has the dominant voice, likely fuelled by its economic power and importance. In the US it accounts for about 18% of GDP, in Canada it's about 11%, and across the EU it's between 7-11%. The sector is also responsible for significant job growth in many economies.

Ironically, health care's economic importance is in contrast to its importance to health. It's increasingly recognised the industry contributes only 10-20% of what we call health.

To talk about health we need to stop talking about just health care.

It's hard to think afresh

Many people are trying to think about health beyond health care but they're more tethered to the bio-medical model than they realise. This often surfaces in evaluation.

For instance, although there are initiatives to address the so-called social determinants of health, their efficacy is measured in bio-medical terms – reductions in morbidity and mortality. This prevents us from seeing the value created *outside* of the bio-medical model – where much of health resides.

Bio-medical approaches are especially problematic because they look for direct, linear causality, something that is hard to find in complex environments. Continuing to use a bio-medical lens in evaluation, then, means interventions at the community level always look 'unreliable' or as if they have 'failed'. This makes it impossible to make the 'business case' for interventions to create health.

If we're going to think about health beyond health care we also have to create the right tools for evaluation.

There's a cacophony of theories

There are too many theories on how to create health.

Many of them overlap and specific theories fall in and out of fashion. 'Learned optimism', for instance, was all the rage after Martin Seligman's 2004 TED talk on positive psychology. Social capital bounces in and out of fashion, most notably off the back of Robert Putnam's 2000 book, *Bowling Alone*. Resilience is currently in fashion, although Arthur Kleinman, the respected medical anthropologist, has recently criticised it, saying that it implicitly suggests people should return to health after a period of sickness whereas the future experience of health will likely be to endure levels of sickness.

While intellectually stimulating, this cacophony of theories does little to catalyse experimentation in the real world – in fact, it largely leads to 'analysis paralysis'. The future of health does not reside in the minutia of academic debate.

Blind faith in Band Aids

Tethered to the bio-medical model and inhibited by the cacophony of theories, our responses to the growing demand for care are nothing more than a collection of poorly fitting Band Aids.

Most of these Band Aids are being applied to the health care sector. Initiatives to integrate services across primary and secondary care or manage patients with complex needs through multi-disciplinary teams *may* improve the quality of care but they do little to create health.

There are many localities, like London, New York and Toronto, where there are numerous world-class health care providers and yet the system still leaks. Safety net programmes mop up the mess, partly masking the inadequacy of the current system.

There is a sense that politicians will keep applying these Band Aids while waiting for the next crisis to give them the political mandate to take action. This seems all the more likely given the diminishing tax base in most countries as a result of smaller working populations in ageing societies.

We're not listening to the people that know

We tend to over-value formal expertise, accumulated through academia, more than we do experiential knowledge or local heuristics.

As a result we wait for experts to tell us what the 'evidence' says, ignoring the people that already know what needs to happen. When it comes to creating health, communities usually know what they want and how they can make it happen. Outside expertise, often in the shape of policy and bureaucracy, only gets in the way.

The health care sector often talks of 'patient engagement' but the bio-medical lens usually – if not always – sets the agenda. There is no sense of health beyond health care so the system is essentially talking to its own agenda rather than understanding the people it's supposed to serve. Sometimes, in fact, this happens in a literal sense, whereby services are created without asking people what their priorities are.

It's time to find parity between formal expertise and local heuristics.

We're not sufficiently aware of those we can learn from

Talk of health care's unsustainability is decades old, and yet little seems to change. One reason seems to be that no one has *shown* us what's possible by creating health. Another is that those making strides in creating health, perhaps through civil engagement or social bonding, are not recognised by the health care industry.

Without a community of practice sharing thinking, projects and experiences in creating health it is hard for others to develop the confidence needed to join in and experiment.

Perhaps one of the most bizarre aspects of this stalemate is how there is much criticism of the idea of creating health – for being nebulous, unmeasurable and unlikely to scale – even though we've barely started.

We're making the issue too big

Too many people believe that creating health is about tackling poverty and inequality.

There is no doubt that poor social circumstances are *correlated* with poorer health outcomes but making creating health about addressing the societal gradient is to make it too big to deal with. Besides, there are many people and communities who enjoy good health, by their own definitions, despite what seem to be poor social circumstances.

Finally, we need to agree on terminology

The bio-medical model's dominance is underpinned by a lexicon that is so well developed that it has a way of reinforcing its world view as *the* world view.

We need to create a lexicon for creating health, one that starts from how people define their health and cuts through the cacophony of theories out there.

Examples illustrating that we've already started

To help them see broader definitions of health the Collaborative reminded themselves of programme and concepts that embrace them

Given the limitations of health care, creating health is an important part of the future.

Like all futures it's already here – it's just not very evenly distributed. There are organisations already experimenting with different definitions of health, and interventions to create and measure it.

There are also organisations changing our very methodologies in health, for instance from waterfall to design thinking. Some organisations have begun to refine and augment their approaches, reminding us of 'the long nose of innovation' – the idea that it can take 20 years for inventive new thinking to become the norm.

Here are four examples starting from communities:

1. *The people of Scotland have decided to focus on children and young people with their 'Getting It Right For Every Child' campaign. Their focus is on wellbeing, which they break down into eight areas: safe, active, healthy, respected, achieving, responsible, nurtured and included.*
2. *'Keep Growing Detroit' is looking to make the downtown area 'food sovereign', which involves transforming people's relationship with food, an important challenge when much of the food in the area was previously only available from gas stations and convenience stores.*
3. *Some initiatives talk about 'asset based community development', the idea of focussing on what communities have rather than what they don't have.*
4. *And in the US, 'community health trusts' are emerging as a way for local organisations to pool resources in order to seed initiatives for community building, such as housing and local workforce development.*

Starting from health care there are now 'health coaches', non-clinical staff associated with clinical services that help patients navigate the health care system and help them to address their social needs. There are also community health workers, members of the community who are trained to deliver basic health care, especially with a view to extend the reach of the health care system.

While both of these approaches start from a bio-medical perspective they have the potential to amplify the voice of the community in the health discourse, potentially making it *less* bio-medical.

Another example is of personal health budgets, the idea that patients are given small budgets to spend on their care. At present, the options available to patients are largely bio-medical, but the programme does pave the way for more flexible thinking on what health is and how people can purchase it.

Creating health is already here – it just needs nurturing to grow and become the norm.

The emerging principles for creating health

Through the day's discussion a number of principles to creating health seemed to emerge



What follows is a list of the principles that surfaced through the discussion. The Collaborative did not necessarily agree that *all* of these are principles, or that they're the *only* principles; these were just the ones that surfaced during the discussion.

Let people define health

This probably goes without saying but let's say it all the same – let people decide what health means to them. And let's not try to enforce any models on them, including the "life satisfaction" one above. Let's just let them speak and take it from there.

Embrace complexity

There's no getting away from it, creating health means trying to create change in a complex environment; embrace complexity, embrace the idea of emergence, focus less on things like causality and attribution and more on shared contribution, and learn to devise projects and programmes within these parameters.

Set a long lead time

Some say the adoption curve is two-and-a-half years. Others say it often takes entrepreneurs and innovators about seven years to create a sustainable business model. There are already projects in health with a 10-year timeline. Whatever you decide, don't plan for less than five years if you want to create a sustainable system of health creation.

Give the community control

Once you understand the different parts of your community, establish a way for the community to be in control. There is every chance that clinical expertise is needed but that skill should be invited to the table as an equal partner, ensuring parity between local heuristics and professional knowledge.

Agree value before metrics

Ensure you agree what value you're trying to create in the community before you start assigning metrics to it. This is essential so that during evaluation you're able to remember the direction you were heading in rather than just the minutia of the journey.

Operate at individual and community levels

Interventions at the individual level are likely to be short term if the interconnectedness – or scaffold – of the community is not considered. Bake this into everything you do by always asking yourself how something that acts on the individual can also either invest in or tell you something about the scaffold.

Accept failure, but fail fast

This is uncharted territory so it's important to take risks. This means accepting the possibility of failure. Borrowing from software development, learn to evaluate early and make quick decisions, whether it be to continue, change or stop a project. Embrace the genuine idea that a unit of success is that you learn something in the process – and ensure that all learnings are carefully documented, including the process that was followed.

Be open to unintended consequences

This is part of embracing complexity but it's worth reiterating within the context of evaluation. Even if you focus on value before metrics, there is every chance you'll miss changes that are happening elsewhere as a result of your intervention. Find a way to be open to this possibility, make space for it in your discussions – there is every chance that new ideas lurk in these phenomena.

Baseline emerging concepts

Although concepts like social capital and asset based community development get much airtime, the evidence behind them is weak. Contribute to the knowledge base by ensuring you understand what baseline exists in your community. In due course you may be able to see correlations between them and the scaffold that can inform creating health elsewhere.

Meticulously record processes

How health is created will differ from community-to-community, but what *may be* the same is the process that's followed. Be meticulous about recording how things are done and why. Transplanting and scaling good ideas will happen at the process level, not the intervention level.

Build a resilient team

Creating health will be difficult work: uncertainty will be the norm, failure will be common, and doubts will surface repeatedly. Your ability to deliver will be directly correlated to how resilient your team is, how much they understand that this is both uncharted territory and likely to be very difficult. Make team cohesion an important metric in your evaluation.

Invest carefully; err towards being lean

At the beginning, you may well require philanthropic capital but consider it only short term, seed funding. If creating health is to become the norm, it must stand on its own two feet – one of consumer-defined value and the other of economic self-sufficiency. To this end, think carefully about loading the endeavour with expensive infrastructure.

Finally, embrace group attribution

The pursuit of attributing causality to single organisation, programme or stakeholder is a red herring. Find ways to attribute value to the commons – whatever that means. This will be fundamental to long term relationships among the multiple stakeholders in a community.

The aegis of community loci

As communities develop loci of control, it will become important to understand what else these loci can do. Given the complexity of communities, it will be important to not assume that a locus for one thing can be a locus for something else. The aegis of each locus needs to be understood and, where possible, built upon.

The idea of collective attribution

The idea of attribution will inevitably surface, especially when there is credit to be taken or blame to be had. We need to understand what mechanisms exist to handle collective attribution to, and, if required, causal contributions from, the various entities that make up the whole.

A community of practice

Communities experimenting with creating health will be at the vanguard and will undoubtedly benefit from learning from one another. But it's important not to replicate the current, technocratic ways these things are done – with experts talking to each other without the community in the room. Communities need to communicate with communities – and in the spirit of learning and collaboration, not competition.

Applaud but question success

Promising initiatives have a tendency to consolidate too quickly, as is the danger for 'health coaching'. It's important to applaud these successes, and learn from them, but also to see them as transient moments from which one can build further. We need to develop a more long-term view of things, perhaps with a greater vision than addressing the now.

Rigour

Creating health and embracing complexity are not excuses for sloppy work. The community of practice needs to define what 'rigorous' means in a world where reducibility, causality and individual attribution are all questioned. This is essential to the credibility of the emerging field.

Appendix A: Members of the Creating Health Collaborative

The attendees and apologies,
alphabetically by first name



*Bridget Kelly**
Senior Program Officer, Institute of Medicine



Gerry Greaney
Designer/Researcher, Center for Innovation, Mayo Clinic



Harry Burns
Professor of Global Public Health, Strathclyde University



Jamie Harvie
Executive Director, Institute for a Sustainable Future



Jeff Cohen
Director, FSG



*Leigh Carroll**
Associate Program Officer, Institute of Medicine



Oliver Smith
Director of Strategy & Innovation, Guy's and St Thomas' Charity



Onil Bhattacharyya
Frigon Blau Chair in Family Medicine Research, Women's College Hospital, University of Toronto



Prabhjot Singh
Director of Systems Design, The Earth Institute



Pritpal S Tamber
Founder, Creating Health Collaborative



Scott Liebman
Partner, Loeb & Loeb (Host)



Seema Kara
Program Manager, US Community Health Systems, Earth Institute



Thomas Foels
Chief Medical Officer, Independent Health and representing the Alliance of Community Health Plans Medical Director For Population Health, HealthPartners

Apologies from:



Esther Dyson
Founder, HICcup



Rick Brush
CEO, HICcup



Thomas Kottke
Medical Director For Population Health, HealthPartners

** The Institute of Medicine's (IOM) guidelines dictate that it can only participate as 'collaborators', not as members; anything that could be construed as a conclusion or recommendation that emerges from the Collaborative cannot be represented as coming from or endorsed by the IOM.*

Appendix B: Words

What follows are words or phrases that Collaborative felt needed discussion in some manner (in no particular order)

Attribution; Toolkit; Navigation; Incubation; Inter-sectorial; Causality; Integrated Care; Innovation; Complex systems; Measures of success; Social failure; Social cohesion; Inclusion; Mobility; Preference finding; Scaffold; Partnership; Health coaching; Platform for change; Scientific rigour; Return on investment; Alignment; Driver; Competence; Multidisciplinary; Culture; Integration; Health dividend; Engineer health into a community (have we engineered sickness into them already?); Self determinants of health versus social determinants of health; Scissor of doom (!); Control; Increasing voice of consumer due to increasing share of spend; Value; Community/citizen engagement; Measurement versus interpretation; Success/Failure; What is innovation, how does it happen?; Multidisciplinary teams (all clinicians?); Model; Impact; Community; Attribution (as a challenge/obstacle); Local; Methods/Methodologies; Developmental neurobiology; Complexity; Chronic; Culture; Agility; What is success?; Citizenship; Change; Expertise; Relationships; Coaching; Disruptive; People vs Patients; Developmental Evaluation; Human centred; Decision makers; Building evaluation capacity; City versus community; Contest versus challenge; Diminishing tax base with an ageing population; Health care versus health production: Collaboration; Co-creation; Holistic care (what does it mean?); Demand; Co-creating (is it real?); Health promotion

THE MEETING AND REPORT WERE
MADE POSSIBLE BY

Pritpal S Tamber

EXPLORING THE FUTURE OF HEALTH



A CATALYST
FOR INNOVATION
IN HEALTH



THE EARTH INSTITUTE
COLUMBIA UNIVERSITY