

A Critique of the Social Determinants of Health Framework and the Real Experience Alternative

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INTRODUCTION

A quick <u>online search</u> of social determinants of health (SDH) reveals hundreds of frameworks of varying colours, shapes, content elements and relations. Each offers a particular conceptual model to help researchers and practitioners understand and intervene in the social conditions, forces and factors that produce disease and differentiate health outcomes and inequities. Despite all frameworks agreeing on the need to intervene in SDH, there are several limitations and consequences when using them to do so. In this article, I provide a summary of these. *I then briefly introduce Umio's alternative real lived experience thinking and framework having potential to address them*.

SDH FRAMEWORK LIMITATIONS

Fallacy of single determinants in the upstream

First, only rarely do individual determinants have a direct causal correlation with discrete identifiable health outcomes, even within narrowly defined places, groups, or populations. Although a clear causal relation can sometimes be found between observable and quantifiable determinants such as <u>dirty air</u> <u>particles and childhood asthma in densely trafficked urban areas</u>, more often, an entanglement of multiple contingent determinants is involved in the production of disease, and even more so in the generation of health inequities. This is especially the case for chronic physical diseases and mental illnesses whose determinants cannot be traced readily to single observable origin risk factors. Rather they are formed from several interacting forces, some observable but the majority usually hidden.

Any framework and analysis of health inequities must then abandon the idea of discrete determinant risk factors, where each risk originates and bears a direct line of causality to an (unequal) outcome. Rather, the upstream-downstream analogy used in common SDH narrative is better characterised as a mangrove swamp of interflowing, connected roots, puddles, bogs, streams and dry land patches whose interactions produce ongoing conditions of *multi-determinant risk formation*. Even in the case of environmentally induced childhood asthma for example, the determinant is not just the harmful particulate matter in the air (the single risk factor) but also the human actions, indecisions, motives, ignorance, exploitation, and discriminations that put and have kept them there. Any upstream determinant then is rarely just a single cause; it is an entanglement of meaning, matter, ideas, tendencies as well as force, and is always connected with other determinants.

Difficulty finding specific mechanisms of disease

Second, and related to the first shortcoming, it is difficult to locate actual specific mechanisms or processes of disease-illness (and especially health) creation in any SDH framework, and especially their origins and formation in upstream entanglements of determinants. This is as true for disease in individual persons as it is for social groups, communities, places, and settings. It is especially true over time. Without knowing specific processes of disease causation, it is hard to gather useful, practical, and clear insight for addressing health inequalities.

Whilst <u>recent research</u> identifies stress as an important pathway of disease causation in individual bodies, there is much to do to understand its different origins. Most stress prescriptions (e.g., mindfulness and resilience building) seek to address its individual expression in bodies, and not its

origination in the conditions and places of everyday social life and encounters. In <u>one school of thought</u>, stress pre-exists its experience in the affective or emotional registers of homes, neighborhoods, communities, workplaces, schools, and environments. When people interact and move within a negative affective register, bodily and mental stress is activated and may accumulate to produce disease and illness. As stress becomes a central pathway in studies of disease causation, SDH prescriptions must find ways to address the wider non-bodily social contexts that bear a potential of excessive stress.

Social context is "everywhere and yet nowhere"

Adding further complexity to a picture of interacting, multi-scale determinants and policies, it seems there are no limits to the social determinants that are now in scope to the SDH framework (WHO now talks of <u>economic</u> and <u>commercial</u> determinants of health also). With wide inclusivity of any social context, it seems there is no context left outside the SDH framework, and therefore nothing that does not mediate our health status in some way. When context becomes everything and everywhere in SDH purview, it is much harder to find a unique material trace of individual contexts in places, settings, and populations (Duff, 2014). In effect, by expanding its scope to all that shapes collective life, the explanatory and practical power of any SDH framework inevitably suffers.

Within-category differences

Most SDH frameworks uses four primary categories of phenomena to produce their explanations of disease causation and inequalities of outcomes, and to guide intervention. These are 1) upstream, midstream, downstream, underlying or wider determinants, contexts, or structural factors of different kinds, 2) individual person lifestyles, behaviours, needs and resources, 3) disease-illness types, their outcomes and differences, and 4) categories of groups, places, or populations of humans in which the three other components are compared and analysed. All four classes contain taxonomies of different representations founded on empirical, sensed, and logical differences in the phenomena they observe and classify. Yet in any single category of representation where there is an assumption of within-category similarity, there is always difference. Whilst the identification of a gradient of health-disease within a population is intrinsic to the SDH framework; for any disease such as type 2 diabetes, there are wide differences not only in its incidence within a population but also differences in the experience of the disease within the disease sub-population. People have different capacities and resources to cope with their condition, differences that often can explain observed inequalities of within-disease outcomes.

Similarly, within any determinant representation, there is difference too. For example, a climate or environmental determinant varies in the intensity, qualities, presence and persistence of its effects, differences that vary in their impact in people's actual experience. Differences in the nature of the climate crisis have differential impact on material resource availability, on community relations, on people's bodies, on anxiety levels, and on perceptions of the future safety of living and working in an affected place, to name a few. When using outcome or determinant categories within an SDH framework, any method must be sensitive to difference within factors, as well as within selected populations or groups. An SDH practitioner must then reflect upon their own tendencies of how they categorise the different elements composing the framework and how this influences their studies and prescriptions.

Confused terminology

SDH frameworks and the discourse they promote lack clarity and consistency. There is little agreement on what is a determinant, what constitutes social, and what is structural. Furthermore, common terms are used interchangeably; a determinant is often described as a <u>factor</u>, <u>condition</u>, <u>force or system</u>, and sometimes a <u>context</u>.

Stability versus dynamism

SDH frameworks tend to freeze the social world to analyse and reveal determinant-outcome patterns and relations. Yet social reality is of course dynamic, processual and in transition. One only needs to think of the great pandemic-induced societal shifts in work, care, place, services and inequalities in the US and elsewhere. The same is true for health itself. It is also a <u>dynamic phenomenon</u>, both individual and collective. Yet again however, SDH thinking uses static pictures of outcomes or end-points in its picture of linear causation. It neglects the moving nature of health and finds it hard to see the transitions in contexts and determinants that result in transitions in health status and equities.

Valuation and normative ethics in the framework

In any SDH-based analysis, program design and funding assessment, there are questions of what constitutes an actual problem or inequality, what should be the goal or purpose of a policy or other intervention, who should be included, what should be the content and timing of the activity, and what should be the level and duration of funding or effort is required. These normative, ethical questions arise in any program but especially when people and communities are not aware of the scale of the inequality they experience, or of what is possible, necessary, or justified. Whilst a framework may provide a (partial) objective data-informed picture of health inequalities, the subsequent determination of priorities and actions involves selection from a wide scope of possibilities. Making such decisions is itself socially determined. They too are based on given ethics of beliefs, tendencies, values and norms, constructions that can be biased and serve to perpetuate inequalities.

The result?

In the above picture of entangled determinants, of everywhere yet nowhere social context, of noneasily identifiable mechanisms, of heterogeneity within representations, and of pre-given potentially biased tendencies in valuation, design, and action, we can see how any SDH framework presents many logical, methodological, ethical, and practical challenges. At any spatial and practical level of analysis and operation, it is hard to know where to start, where to focus and what exactly to change.

Fundamentally, by reducing disease-illness origins to discrete determinants, risk factors and outcomes, the ontology and epistemology of SDH frameworks neglects the intrinsic complexity of people's lives. They fail to see and understand how important differences in real experience play out across and within categories of determinants and social context. Consequently, they are unable to produce the deep insights needed to guide actions that reduce health inequalities and disparities on a sustained basis in specific places (Williams, 2003, Shim 2014). The SDH framework only "goes around" its object of health; it does not enter sufficiently deeply into health to understand its diverse

experience, their origins, formation, differentiation, and persistence. With social context, heterogeneity, and uncertainty everywhere, current SDH frameworks can only ever direct us to pull at different strands of determinants of (unequal) health problems in an experimental fashion based on what is or can be measured, correlated and is notionally ethical.

Summary

Given the above challenges, using current frameworks to research and address social determinants is akin to chasing a rainbow. They shift around depending on our perspective, position, purpose and method. They can be present and yet not present in the same place at the same time. Whilst SDH frameworks justifiably widen the purview of possible and necessary action on health and health inequities, they struggle to guide useful action at scale and with enduring impact. It seems it is hard to find a pot of gold at the end of any SDH framework.

AN ALTERNATIVE FRAMEWORK – ASSEMBLAGES OF REAL EXPERIENCE

A fundamental weakness of all SDH frameworks is that they neglect the particularities of people's lives. They tend to reduce, abstract, and generalise people's concrete real experiences with health, disease, and illness. I suggest therefore that any alternative framework must start with **real experience** as its focal phenomenon of interest. It must then have the same ambition of any SDH framework – to capture novel insight and guide impactful interventions into health and disease origins, formations, inequities, and their recurrence.

A model of real experience with health and their interactional creation

To begin addressing this ambition, as I did so eight years ago, we must first choose a theory and build a model of real experience. Doing so allows us to see the presence, mechanisms and differentiating forces of outside social and structural determinants, contexts, and risk factors *within* experience itself. Importantly, I define real experience as a more-than-embodied system of brain-body-environment interactions. This view of experience goes beyond a narrow view of conscious experience that senses and processes the world in a mind-independent way.

The figure below depicts a whole dynamic processual model of interactional creation of real experience (with health). At the centre of the model are the core generative material of real experience – the sensations or affections we sense and feel, and the different affective capacities we acquire, possess, and deploy to affect and to be affected in our everyday interactions (in the places and spaces we live).

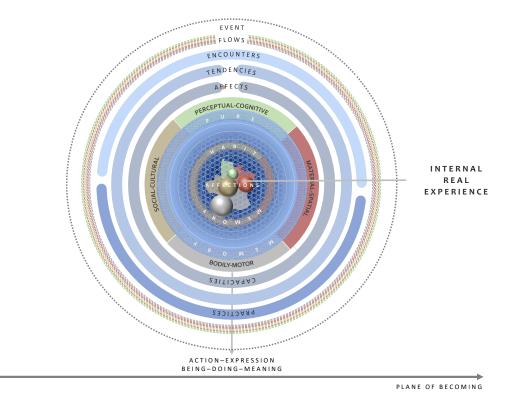


Figure One: Umio Model of Interactional Creation of Real Experience

A world of flows of similar real experience

With a model of interactional creation of real experience defined, I then consider how there are similar real experiences shared by people and communities in the world. We can think of how such experiences flow, meaning that they are always becoming, intensifying, and dissipating through and within certain groups, settings, communities, and populations as well as individual persons. These contexts of flowing real experiences span and integrate bodily disease or illness contexts such as pain and respiratory disease, mental contexts such as depression and anxiety, and more social contexts such as stigma, loneliness, and injustice.

Focal real experience ecosystems as a new framing device

When we envisage a world of flows of similar collective real experiences, we can place a loose open frame around a particular flow of a certain context or contexts. I call this frame a *focal real experience ecosystem*. It is a cut-out of the flowing reality of a defined health context of real experience that includes human actors and their performative practices, non-human or human-made and/or influenced actors (environmental, climate, spatial, material, technological) (collectively I call these affectors) and all their tendencies, forces, factors, percepts, affects and affective capacities. Together, all these elements originate, form, differentiate, move, repeat, and can eliminate or recover the focal context of real experience.

An experience ecosystem sets a novel frame for acting on the mechanisms of health-disease creation in a wide sense. Using an experience ecosystem, we ask not just "what are the differences or the inequalities of health or illness" but also questions of their formation, differentiation, and repetition. We problematise creation itself. This can be done for a chosen context of real experience with health within a particular

or type of place or community, group, setting and population. For example, in my work and teaching, we have explored the experience ecosystem of chronic pain in Northern Ireland, of healthy ageing in Long Island, of young person ennui in Arkansas Delta small towns, of workplace wellbeing in Germany, and of all actor experiences of safety provision in acute care settings.

Next, for any focal real experience context such as experience with chronic pain, obesity or loneliness, a temporal context such as adolescent development or a wide-frame such as place or community consisting of multiple contexts, we can identify extremes of positive and negative qualities and affective capacities for that context, as follows:

- An ill-health experience pole that defines the worst affect quality and affective capacity. Here the flow of real experience is stuck or sedimented. There is a low power of affective capacity to act on the experience to change it. The experience is spatially constrained, time-regulated and deprived of possibilities.
- A desired (valued) experience pole that contains the most desired affects and affective capacity. Here there is a diversity of affect creation arising from agreement and fluidity in relations and interactions with affectors, an intensity of real experience that generates and augments a power or capacity of acting, interacting, and creating.

In Figure Two below, I depict the two poles together with brief descriptions of the opposing qualities of affects and affective capacities characterising each.

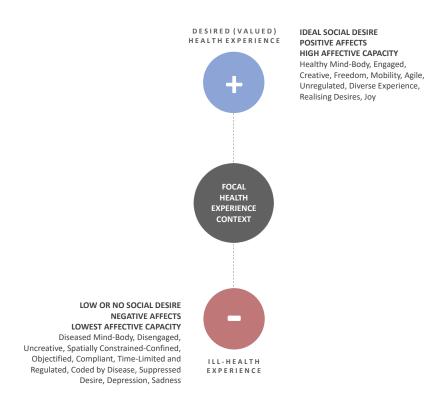


Figure Two: Poles of positive and negative experience with health/wellbeing (or just human being-becoming) qualities (I call social desire)

Using these poles, we can research and discover the current distribution and trajectories of movement between the poles for a focal real experience context. We do that through the lens of assemblages of real experience (AREX).

Assemblages of Real Experience (AREX)

Assemblage thinking (Deleuze and Guattari, 1987) provides a framework for seeing and understanding the dynamic production of real experience from intensive interactions of relations of desires, forces, and affect with bodies in their environments. For a detailed explanation along with models and examples of assemblages of real experiences with health, see Lawer (2021).

An assemblage is a dynamic relational arrangement of enfolded social and structural tendencies, human and non-human actors, forces, desires, affects, capacities, and material objects (including digital technologies and drugs) forming a particular **enduring quality, content, and expression** of real experience in an experience ecosystem. It also defines the status and possibility of its movement or transition from one assemblage to another.

For any focal context such as chronic pain, we can identify an assemblage of assemblages of real experience that exist around the positive and negative poles shown in Figure Two. There are assemblages of real experience on a line of deterioration to the negative pole, and assemblages on a line of recovery to the positive pole. Below is an example of the high-level output of assemblage research from the 2019 Umio study chronic pain real experience in Northern Ireland (featured in Lawer, 2021). This shows six contingent dynamic assemblages, the numbers in the pain population belonging to each and the transition states between them.

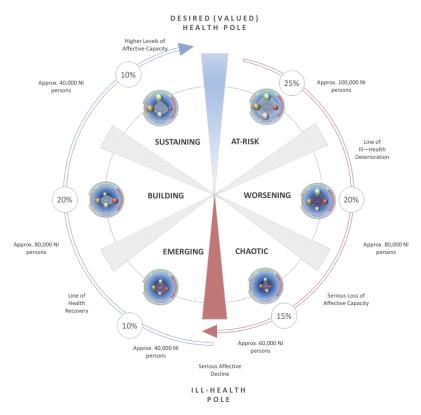


Figure Three: Assemblage of chronic pain real experience assemblages on a line of deterioration (right-hand side) and line of recovery (left-hand side)

With the assemblages defined from immersive ethnographic and some quantitative research, we then embark on the transition design and creation process. Briefly, this runs as follows:

- 1. Identify the desired transitions within the assemblage of assemblages
- 2. Reflect on the tendencies of current thinking and practice that are present in the flows of forces and experience ecosystem
- 3. Set a series of challenge questions to help unlock our path to impactful design
- 4. Co-create ideas and concepts to undo the tendencies and enact the desired transitions
- 5. Define a multi-parameter dynamic value model, one that focuses on assemblages of affects and affective capacities as meaningful value-creation
- 6. Organise, implement, assess, and refine on an ongoing basis

The full learning and design process is set out in comprehensive detail along with templates in the Umio book *Interactional Creation of Health: Experience Ecosystem Ontology, Task and Method* (Lawer, 2021).

SUMMARY

To better address the social determinants of health, I argue for a new real experience-centred framework, one that reveals assemblages of real experience in situated focal contexts and that guides us to more impactful actions in their various contingent states and transitions. If we are to have real impact in health problems and their inequities, we need a more radical empiricism of health, illness and their formation, one I argue that must be centred foremost on real experience.

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