

The Living Declaration of Disability, Resilience and Equity

“Of all the forms of inequality, injustice in healthcare
is the most shocking and inhumane”

- Martin Luther King, Jr. - 1966

BACKGROUND

In the Summer of 2019 an international community of researchers, artists, practitioners, politicians, and activists gathered in the historic city of Elsinore, Denmark for the REIMAGINE Action Lab and Festival, hosted by Enactlab. The goal was to explore how to REIMAGINE disability in the 21st century. What emerged was the fundamental importance of promoting equality and equity of people with disabilities/disabled people* and the need to collectively raise the voices of people with disabilities/disabled people across geographies and cultures.

In March 2020 the REIMAGINE community reunited once again in order to develop a collective response and action to the ongoing COVID-19 pandemic. The Living Declaration emerged as a collaborative statement designed to catalyze awareness, dialogue and collective action in communities around the world.

PREAMBLE

The Universal Declaration of Human Rights by The United Nations states that all human beings are born free and equal in dignity and rights. Despite this declaration, in the midst of COVID-19, and beyond, it is clear that people with disabilities/disabled people do not have equal rights and access to basic healthcare, food, water, and security. People with disabilities make up 15% of the world's population but, have increased chances of disease and higher rates of poverty than those who are not disabled. The Covid-19 pandemic is similarly affecting people with disabilities/disabled people disproportionately.

This virus does not appear to us as a great equalizer. It is, instead, a great revealer. It reveals inequalities and inadequacies. It reveals class and racial divides. It reveals the gap between those who are able bodied, non-disabled and those who are disabled. It reveals and augments pre-existing inequalities in access to care, distribution of resources and mortality from illness.

This crisis cannot become another opportunity for governments to impose austerity, erode individual rights and violate their responsibilities to the people. We must seize the moment of crisis from those who would use it to reinforce these inequalities:

It must be a moment to REIMAGINE our unequal and uneven healthcare and social structures. Now is the time to call for a reinforcement of global structures that would support and protect our most vulnerable individuals – and to make these structures and systems even more resilient.

The REIMAGINE community has come together across cultures, nationalities, gender, age, and profession to form a declaration in response to the lack of focus and clear action for people with disabilities/disabled people, in the midst of the COVID-19 epidemic.

We present this declaration not as a finite set of demands and acknowledgements, but instead as a catalyst toward collective dialogue and action – across communities, cultures and continents. Therefore, we call it **“The Living Declaration”** of Disability, Resilience and Equity.**

**We recognize that the term disability varies between people, societies, cultures and contexts. We acknowledge that there is no single right term, phrase, or word for disability that captures the full diversity of lived experiences and socio-cultural understandings of language. We believe that disability can be biological, psychological, and social in relation to the individual and society. “E.g.: We acknowledge the term “D/deaf and disabled people” in the United Kingdom as an example of the variation of the term disability.*

***We recognize the imperfections of written language in attempting to create a universal declaration, especially working across cultures and a broad diversity of embodied understandings of language. Thereby we attest to the need for constant dialogue, so we can transcend the challenges of the written word, through exchange, learning and the ambition to work toward collective action*

Article 1

We reaffirm the dignity and equal rights of all human beings, and therefore emphasize that all People with Disabilities/Disabled people have the right to participate wholly within the fabric of society without discrimination and marginalization.

Article 2

In moments of global crisis, quarantine and isolation – it is more important than ever to reaffirm the interconnectedness of all human life, and actively work toward strengthening our relationships and solidarity across communities and cultures, through exchange, dialogue and collective action.

Article 3

In times of resource allocation, manufactured crises and critical shortages – such as COVID 19 – we must reaffirm that all People with Disabilities/Disabled people are valid in their needs and expectations in upholding all rights accorded to personhood – physically, psychologically and socially.

Article 4

Health and well-being is a human right; therefore, our healthcare systems must promote equity, accessibility and diminish disparities. Consequently, in health and across society, we must promote a culture of solidarity and cooperation, instead of individualism and competition.

Article 5

People with Disabilities/Disabled people have equal rights and access to the comprehensive healthcare they require for their health and well-being throughout their lives, and therefore:

- Healthcare must be accessible at all levels for people with disability - physically, psychologically, and social - in relation to the individual and society.
- People with disabilities/disabled people have the right to be treated with dignity and respect by healthcare organizations and workers.
- In times of crisis and beyond, we must resist all discriminatory triage protocols that withhold resources based on erroneous presumptions about the lived experience and value of People with Disabilities/Disabled people.

Article 6

People with Disabilities/Disabled people have the right to the same level of information and access to media/communications platforms during the COVID-19 crisis and beyond. This means:

- All information and communication pertaining to any aspects of the COVID-19 crisis – social, political, health, educational and otherwise – must be fully accessible to everyone (sign language interpreters, lip speakers, notetakers, audio describers and other language translations must be available).
- Media and communications platforms must highlight and provide space for the voices and lived experience of all vulnerable groups, including People with Disabilities/Disabled people.
- Disabled people/People with Disabilities with communication requirements have the right to have an interpreter at all times, in relation to health and other issues with COVID-19 and beyond.
- People with Disabilities/Disabled people have the right to have a support person assist them, as required, in relation to health and other issues with COVID-19 and beyond.
- The healthcare system must enact appropriate measures to give People with Disabilities/Disabled people equal access to communication with the healthcare provider that any other patient would receive.

Article 7

We acknowledge that People with Disabilities / Disabled people are more at risk and vulnerable during times of crisis and therefore:

- Affirm the need to equitably provide the support and services needed to overcome challenges of self-isolation or quarantine and diminished access to necessary support staff and structures.
- Recognize that there are often additional financial considerations that come with various disabilities and that these financial needs should be supported by governments to ensure equitable access to all essential care and needs.

Article 8

Moments of crisis demonstrate how quickly policy changes and accommodations in the workplace and beyond can be made for all people. We must ensure that any and all accommodations required by people with disabilities/disabled people to live and work at their full potential are swiftly enacted at all times, without discrimination and prejudice – not merely in moments of crisis.

Article 9

We must strengthen and expand community and family medicine practices in order to provide more responsive, humanistic and person-centered healthcare for People with Disabilities/Disabled people and all human beings – both in moments of crisis and beyond. We recognize the need for employing the pedagogical shifts and practices required to provide greater autonomy and health promotion at the community-level.

Article 10

Moving forward, all healthcare workers and medical professionals must receive disability equality and awareness training to prepare them for direct experience working with People with Disabilities / Disabled people (E.g.: Deaf equality and awareness; mental health training, etc – led by people with disability, disabled and deaf leaders)

Article 11

Henceforth, all government and policy bodies must include a disability advisory board in their organizational bodies to ensure that the needs of People with Disabilities / Disabled people are recognized in **all** plans, policies, projects and initiatives.

Article 12

We must work closely with international organizations, including the United Nations (UN) and the World Health Organization (WHO), to guarantee that the general principles of the UN Convention on the Rights of Individuals with Disabilities are effectively applied and enacted in every nation, in order to achieve universal well-being. These principles include non-discrimination; accessibility; equality of opportunity; and full and effective participation and inclusion in society.

Article 13

It is essential all government bodies must coordinate appropriately to ensure that People with Disabilities / Disabled people have reliable access to medical services, as well as sources of food supply. Access must involve the provision of some form of safe transport to persons with disabilities, particularly low-income individuals living in both rural and urban communities of concern. In other cases, it will entail employing transport to provide these services and foodstuffs to persons with disabilities that cannot leave their homes.

Article 14

We understand that the experiences and voices of young People with disabilities/Disabled people are essential to emerging debates and collective action on disability in order to make changes relevant and meaningful for generations to come. We recognize the importance of becoming active agents of society, of obtaining an education, employment, independence and autonomy, housing and independent living, and the possibility of promoting positive social change.

Article 15

We recognize the dynamic and diverse nature of the lived experience of disability and actively encourage a global dialogue to continue expanding the scope of this declaration and its active implementation in communities, organizations and governments across the world.

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The Living Declaration is an initiative of Enactlab



Enactlab is an international knowledge lab, combining the lived experience of people and society with the methods of the Enact Model in order to enact meaningful change and agency.



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