

**The Dignity Project
Values and Operational Commitment**

July 2020

Content

Purpose 2

Definitions 2

Background..... 4

Values..... 5

Framework..... 6

Commitment 7

Purpose

This document was designed to provide operational guidance and transparency for The Dignity Project research team. Created by people with and without disability, the definitions, values, frameworks and commitments outlined by this document are a result of the preliminary work of The Dignity Project Pilot. It is the hope of The Dignity Project that others, particularly researchers, will adapt and implement the values and commitments outlined below in order to work toward more accessible and inclusive spaces and practices.

Definitions

Disability

The Dignity Project recognises disability as stated in the United Nations Convention of the Rights of Persons with Disabilities (CRPD)(2006) stating, “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others” (p. 2).

Impairment

As outlined by the World Health Organization (2011), impairments include physiological functions of the body systems and/or body structures that, when combined with environmental and attitudinal factors, causes the individual to experience activity limitations and participation restrictions.

Support network/supporters

The Dignity Project promotes individual autonomy and independent action and endeavours to embed those values into the language used. When discussing the individuals and community of people that play active roles in the facilitation of the daily life of a person with disability, we will refer to them as supporters or a support network.

Citizen(s)

Recognizing that all people are members of a greater, global Human Commonwealth, citizen refers to any and all people. If research, writing, or other scenarios require the identification of a population of citizens, then The Dignity Project supports doing so only in dignified language and only when truly necessary. For example: The Hopkins Centre researchers and a group of citizens with lived experience of disability will conduct this research.

Accessibility

Accessibility refers to the respectful and equal design and delivery of services, products, and environments (physical or otherwise) so that all citizens are able to utilize them “to the greatest extent possible, without the need for adaptation or specialized design (The Centre for Universal Design). The World Health Organization (2013) outlines three types of accessibility: physical, economic, and information. Physical accessibility means that “health facilitates, goods and services must be within safe physical reach for all sections of the population” (WHO, 2013). It further states that it is “understood as the availability of good health services within reasonable reach of those who need them and of opening hours, appointment systems and other aspects of service organization and delivery that allow people to obtain the services

when they need them” (WHO, 2013). Economic accessibility is defined as “a measure of people’s ability to pay for services without financial hardship” (WHO, 2013). This factors in the financial cost of health services but also “indirect and opportunity costs” Information accessibility is the “right to see, receive and impart information and ideas but “should not impair the right to have personal health data treated with confidentiality” (WHO, 2013).

Inclusion

The Dignity Project understands and refers to inclusion as the equal participation of all citizens in all aspects of life, including the redesigning or creating of products, services and environments with the greatest diversity of people in mind and involved in the creation process. Inclusion is not just participatory or representative, but includes the practicalities of work, engaging citizens more centrally to have a great impact on methods, outcomes and results.

Dignity

Dignity is a concept that is easily discussed but difficult to define and understand. It is used frequently as a guiding principle for best practice across a range of disciplines and industries. The United Nation’s Universal Declaration of Human Rights (1948) refers to dignity in that “all human beings are born free and equal in dignity and rights”. It goes on to specify in Article 2 that dignity is afforded to people “without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status” (United Nations, 1948). It is the goal of the Dignity Project to develop a deeper understanding of what dignity means and how it is understood and experienced by people with disability.

Background

The Dignity Project is presented by The Hopkins Centre: Research for Rehabilitation and Resilience and the Queensland Government, Office of the Queensland Chief Scientist.

The Dignity Project is a research and citizen science initiative aimed at disrupting stereotypes and breaking through barriers that people with disabilities experience every day. Whether overt or covert, deliberate or unconscious, these barriers lead to undignified treatment and exclusion. The Dignity Project wants to inform disability reform for the future and will learn from the past and stories that would otherwise remain untold. Through stories, we can illuminate future possibilities, but also pathways that should never again be travelled.

Funded by the Office of the Queensland Chief Scientist, Citizen Science grant, The Dignity Project Team is made up of people with disability and people without. At the intersection between human experience of disability and science, The Dignity Project uses a digital engagement and analysis platform, where people with disabilities can share, reinterpret, and analyse their collective experiences. It also features citizens and researchers co-designing research as well as service and system innovations for the future.

The Dignity Project team understands that people with disability are the experts of their experiences and strives for research to reflect that, intentionally using the word 'uncover' in our research framework as a reminder that experiences of dignity and indignity are not new, we are simply using different, more inclusive techniques to uncover them. The project team takes a holistic approach to research and is guided by the outcomes of citizen engagement.

This is a living document that outlines the values and operational commitment of the Dignity Project. It will help The Dignity Project and Hopkins Centre to use the most efficient and inclusive systems, processes and language throughout the delivery of the project and beyond. It can be used to support conversations and communications about The Dignity Project with external stakeholders, including citizens, research partners and media.

Values

As a project run through The Hopkins Centre (THC), THC's core values are also the underpinning values of The Dignity Project.

THC strives to find better solutions to complex systemic challenges through collaboration and responsive research that is embedded in practice and engages citizens with lived experience of disability. Meaningful accessibility and inclusive practices underpin all aspects of the values of THC. Our values ensure that our research and daily operations will uphold the dignity of all people, through the use of dignified language, methods and the recognition of experiential knowledge. Our research will:

Facilitate choice

The Hopkins Centre firmly believes that citizens have the right to run their own lives. We support individual autonomy and independent action, as well as each individual's ability to create their own pathway with the acknowledgement that interdependence and support is often an essential part of a person achieving their goals. As such, we will work to remove barriers that hinder full and effective participation and ensure equal accessibility and inclusion for all people.

Promote authentic representation

Imagery and media play a powerful role in the way people perceive themselves and others. Part of creating inclusive environments and experiences is ensuring that imagery and media are reflective of the real-life experiences of the broader community but particularly the specific community being represented. We understand that it is our responsibility to create and utilize imagery and media that reflect the real-life experiences of citizens when accessing/using medical services; this includes ensuring that images reflect diversity of impairment.

Expand opportunities

The Hopkins Centre appreciates the important role of citizen perspectives in informing the design of services and social interfaces. Our goal is to expand on and create equal opportunities by opening pathways and building capacity through research outcomes as well as for citizen researchers.

Enhance potential

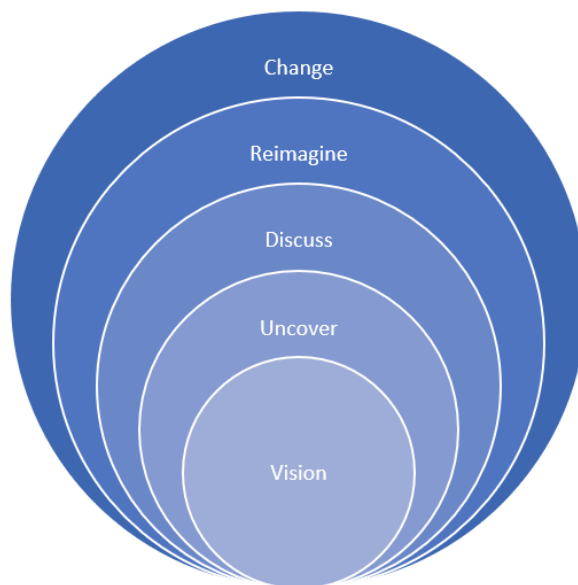
The Hopkins Centre recognizes the potential in citizen research and supports citizens to see potential in themselves. By employing Universal Design concepts to evaluate our systems and processes, we can provide a number of options for individual participation. THC strives to meet people where they are at, providing flexibility and freedom within our work to allow for meaningful accessibility and inclusion.

Engage people and their support network

Support and engagement of citizens with lived experience of disability, including the engagement of support networks, families and social networks continues to be a predictor for positive health and quality of life outcomes. The Hopkins Centre works to be a mechanism for engagement and support, involving members of support networks in research and practice in order to prevent exclusion.

Framework

The Dignity Project has established a citizen science research framework to assist in communicating and guiding our research. This was adapted from the “Our Voice” Framework created by Stanford University.



Vision:

Citizen scientists are embedded within the research team in order to develop research aims, questions, vision and overall research design. Based on the cry of the disability rights movement, “nothing about us without us”, this framework supports research that is grounded in a community perspective to find solutions to problems that are needed by the community. Using the principles of co-design, citizen scientists are not consulted only at the start, but included throughout the data collection, analysis, and production of final outcomes.

Uncover:

Citizen science participatory research is conducted through accessible digital platforms and solutions to uncover problems, barriers, solutions, experiences, and information. The word ‘uncover’ is intentionally used as a reminder that the experiences being uncovered through data collection and the resulting outcomes are owned by the citizens. Data collection in this way is not about collecting or discovering something new, but using methods that are accessible and allow for the uncovering and exposure of issues and experiences that are inherent to the community.

Discuss:

Following data collection, citizen scientists, key stakeholders, researchers, and the members of the research team come together to analyse and discuss the data in order to develop inclusive outcomes and solutions. Whether through a steering committee, key informant interviews, focus groups, or a member checking process, the discussion of the data should include the greatest diversity of perspective and experience.

Re-imagine:

Co-designing and co-creating a new picture and understanding of concepts, theories, outcomes, and solutions as uncovered in the data and discussed with a diverse group of collaborators. The results should involve actionable, operational, and/or educational elements that can be used to drive change.

Change:

Research should be done in order to result in meaningful policy, practice, social, attitudinal, environmental and/or systemic change that ultimately leads to a more inclusive and accessible society. Research teams should pursue an empowering agenda that will result in actionable outcomes to produce change for the members of their citizen science community.

Commitment

The Dignity Project is committed to upholding the rights of all people, in particular the rights of people with disability and strives to create a research environment free from barriers to participation. The below commitments are the mechanisms to help us bring our values to life in day to day operations.

Our commitment:

1. Use language that aligns with aforementioned values

The Dignity Project recognises that everyday language plays an influential part in forming people's perceptions and identities. The Dignity Project and The Hopkins Centre will use person first language, focusing on the individual first and if at all, a disability or impairment second. We recognize and uphold each individual's right to self-identify what terms, pronouns, and language is best for them and we respect individual use of language and terminology.

Please note the following section refers to external communications and does not override that we will respect and use a person's preferred language when referring to them in communication or when referring to them specifically in external media.

The Dignity Project will:

- As per the United Nations Convention on the Rights of Persons with Disabilities, all communications and media will refer to individuals or the collective as a 'person with disability' or 'people with disabilities'
- Not use euphemisms such as 'differently-abled' or 'different abilities'
- Not use words that present impairment negatively such as 'suffer', 'stricken', 'afflicted', 'tragic', 'dependent', 'victim' or use words that patronise or exaggerate basic human experiences by using words like 'inspirational'
- Not use pejoratives that derive from diagnostic language or medical terminology
- Where relevant, when referring to a person's use of any assistive aid/device we will refer to the person as the 'user' e.g. "wheelchair user" not "wheelchair bound".

2. Embed accessibility into development and prototyping of all experiences

Consideration for accessibility and user testing encompasses online environments, content and resource creation, visual media, physical spaces and support. To ensure citizens with disability can access and utilise The Dignity Project webpage, Community Hub platform and resources, accessibility experts will be engaged during development and accessibility audits will be performed. The Centre for Accessibility (CFA) is a partner on the Dignity Project and have resources available: <https://www.accessibility.org.au/>

The Dignity Project will:

- Engage CFA at specific milestones throughout product and resource development
- Ensure all technical partners and contractors are familiar with most recent WCAG standards and implementation
- Undertake internal testing
- Provide resource material in a wide range of accessible formats e.g. Easy English, visual media, screen reader friendly documents etc.
- All visual media will be accompanied by 'alt text' or image descriptions, closed captioning and audio description or transcription
- When working closely with people with disability, an individualised approach to access will be taken e.g. The person will be asked what support they need to participate effectively

3. Promote authentic representation as per core value

We understand that it is our responsibility to create and promote imagery and media that reflect the real-life experiences of citizens.

The Dignity Project will:

- Consider messaging and framing and all facets of diversity including diversity of impairment when selecting and using imagery
- Where stock imagery fails, create imagery
- Engage people with disability in image selection

4. Ensure diversity of experience

The Dignity Project recognises the value of lived experience in research and the importance of engaging people with disability from a diversity of backgrounds in development and design. The project team will be strategic about their approach to recruitment and citizen engagement ensuring that diversity and intersectionality are considered.

The Dignity Project will:

- Develop an impact and distribution strategy that includes organisations that represent Culturally and Linguistically Diverse (CALD), First People and LGBTQIA+ communities and a variety of disability organisation and service providers
- The project team will engage CALD, First People and LGBTQIA+ community members when creating relevant research questions, surveys, content or media
- Actively seek and support research staff/contractors with disability

