

Creating systems that increase dignified experiences for people with disability

Industry Report

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A Note on Terminology

The Dignity Project recognises that everyday language plays an influential part in forming people's perceptions and identities. The Dignity Project uses person first language, focusing on the individual first and if at all, disability or impairment. We recognise and uphold each individual's right to self-identify the terms, pronouns, and language that is best for them and we respect individual use of language and terminology. Where a person does not state their preferred language, person first language is used.

Disability, in the context of this report, is grounded in the *United Nations Convention on the rights of Persons with Disabilities* and is conceptualised as resulting “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” (CRPD, 2006).

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PLEASE NOTE The views expressed in this report are not necessarily those of any of the departments or agencies that participated in this research.

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Introduction and project context

The Dignity Project is a research and advocacy initiative of Griffith University and a flagship program at the Hopkins Centre. It was developed in response to research that revealed that people with impairment experience violations of dignity and suffer inadvertent harm through systems of care. The Dignity Project is led by people with disability and academic researchers in partnership to deliver meaningful outcomes and social change which promote dignity.

The Dignity Project is currently funded in part by the Motor Vehicle Accident Insurance Commission, the Department of Transport and Main Roads, and the Gold Coast Hospital and Health Service to conduct various research activities on dignity in systems for people with disability. It was previously funded in part by the Queensland Office of the Chief Scientist. Additionally, the Dignity Project is committed to privileging, partnering, and employing the voices of lived experience in research to retain consumer leadership throughout the lifecycle of research.

Scope

Over the past two years, The Hopkins Centre has undertaken a suite of projects within the Dignity Project flagship program to understand what dignity means for people with disability and how to ensure that people with disability have dignified experiences in their interactions with mainstream services and systems. The appendices contain details and key achievements of each of the 4 studies.

This resource was developed for policymakers, system and service managers who have an interest in ensuring that the systems and services that they design and manage promote dignified experiences for people with disability. Our hope is that by following four strategies and recommendations outlined in the resource, you can transform the experience of people with disability in complex systems from one in which dignity violations happen all too often, to one in which people with disability feel dignified, welcome, respected and safe.

Systems change is key to our approach. The literature on dignity, in particular violations of dignity, often focus on specific interactions or occasions which leave people feeling as if their humanity has been ignored or degraded in an important way which diminishes their sense of self-worth, in addition to other more visible and palatable harms. While it is important to address the behaviours and attitudes that precede such problematic events, it is also important to understand that there are other factors- environmental (including built and online environments), legal and policy factors, service and/or program design- which create the conditions in which undignified interactions occur.

Defining dignity

Dignity is a complex and multifaceted concept with a range of bioethical, philosophical and practical considerations.¹ The provision of dignity for people with disability is enshrined in numerous frameworks and pieces of legislation, including the *United Nations Convention on the Rights of Persons with Disabilities* (2006), the Australian National Disability Strategy, the Australian Charter of Healthcare rights, and so on. Despite different juridical origins, these documents all point to a multifaceted mandate for dignified treatment of people with disability across systems and services. First, dignity signals respect and thereby enacts human rights and second, it increases engagement of people with disability in services and systems, thereby promoting better life outcomes.¹

Dignity is typically conceptualised as either inherent- something that people are entitled to on the basis of rationality, agential action and autonomy²⁻⁶ or as contingent- influenced and potentially violated by personal, cultural, societal and relationship factors.⁶⁻⁸ Both conceptualisations of dignity present challenges for people with disability. People with disability are often denied full status as ‘human beings’ by legal and societal norms and may experience limits to functional capacity as related to autonomy, rationality, and independence.⁹⁻¹¹ For people with disability, overt, covert, deliberate and unconscious barriers across all aspects of engagement with systems and daily life, increase vulnerability to violations of dignity. Therefore, despite the critical importance of dignity as articulated in legislation and frameworks, and as supported by people with lived experience of disability, it is necessary to move away from current conceptualisations of dignity, steeped in the normative dynamics of ableism.

2.1 Defining dignity with people with disability

“Dignity is being able to have the same opportunities, relationships and experiences as everyone else, and to be treated with the same love, respect and appreciation” (DP Participant).

People with disability who participate in the dignity project defined dignity in a range of ways relating to individual personal factors, community factors, system and structural factors. This report focuses on the conditions within systems that can be improved or changed to maintain dignity. It is worth noting, however, that given the persistence of entrenched inequalities for people with disability, there are significant challenges to developing the conditions that support a sense of dignity. For example, some participants indicated that paid employment promoted a sense of personal dignity. While it is important for rehabilitation services to support vocational rehabilitation and develop pathways for economic participation, for example, whether or not someone has a job cannot be determinative of whether a service treats them with dignity.

When interacting with systems, dignity is predicated on the system—and people that make up the system—acknowledging and respecting people with disability as human beings. Acknowledgement comes in equitable and equal access to systems and services and the ability to independently navigate and sense-make about engagement with systems. The people that work within a system, specifically frontline and clinical staff, greatly influence dignified interactions and an overall sense of dignity, as the tenor in which care is respectfully provided, allows people with disability to feel respected and acknowledge as individuals with diverse preferences and voices. Finally, respectfully engaging with and acknowledging the choices, preferences, and agential nature of people with disability, contributed to holistic sentiments of dignified interactions.

2.2 The importance of dignity for people and systems

“you feel not worthy, to be honest, you feel like less than a human” (DP Participant).

The impact of dignified and undignified treatment simultaneously impacts on people with disability, members of their support network, and on the systems and services with which they interact. Dignity is an upstream determinant of participant's experience of care in health systems, as it can directly influence patient and customer satisfaction, feelings of personalisation of care, and the delivery of optimal preventative services.³ Undignified interactions with systems and services can increase people with disability's feelings of dissatisfaction and humiliation, can lead to withdrawal and social isolation, and can increase the risk of chronically poor physical and mental health.⁹⁻¹³ Mistrust and dissatisfaction can result in an increased chronic cost to government and insurance funders, who are required to support daily living for longer and to potentially greater levels.

Indignity can contribute to potential loss of customer/client or a reduction in utilisation of services. Increased risk of complaints is also indicated by participants who experience undignified interactions, particularly those experiences that involve negative staff attitudes and unsafe feelings. Reputational risk is another potential impact identified by participants with disability, who tend to be loyal to businesses and brands that treat them with dignity. With the prevalent use of social media, reputational risk poses an important potential positive and negative impact for many services and systems, especially as stories involving people traditionally viewed as 'more vulnerable' are often national and newsworthy.

Feelings of indignity often cumulate, contributing to anxiety, irritability and frustration. Some research participants reported suicidal ideation following repeated violations of dignity in systemic contexts: health and employment. For participants with acquired neurological impairments, dignified interactions and treatment, particularly in rehabilitation and health service settings directly following the acquisition of impairment, was critical to maintaining dignity. Our research indicates a juxtaposition between life before, living as a non-disabled person, and a new life after acquisition of impairment. The difference in care tenor and treatment before and after impairment was noted as somewhat different to what they experienced prior to acquiring their impairment, making them more vulnerable and perhaps more sensitive to experiences of indignity.

Recommendations

3.1 Eliminate or minimise access barriers

“We live in such a hostile environment. The built environment is so driven by risk management and limits. It’s not human centred. For me, a hospital is a really hostile environment. It’s really noisy and bright” (DP Participant).

3.1.1 Key definitions

To have access means that you have the opportunity, means and right to enter (infrastructure or conveyance) or participate (in e.g. service or activity) or use (e.g. resource or information) a system or service. People with disability are often denied access when they are not allowed or afforded the opportunity to access a system or service, when they are not provided with the means or rights to participate, and so on. Facilitating equitable access to comparable opportunities and experiences is critical for dignity.

3.1.2 Key findings

Physical accessibility and inclusion in built and online environments critically impacted on participants with disability’s sense of dignity. Participants discussed the importance of feeling welcomed and included by systems when there were few or no barriers to access and inclusion. Barriers, whether overt, covert, deliberate, or unconscious negatively impacted on participants by creating a sense of dependency, increasing anxiety and emotional distress, increasing social isolation and vulnerability, and avoidance of opportunities. Dignified interactions were shaped by interactions between people, infrastructure, the physical, cultural, digital and social spaces they traversed. Dignity as created when the built physical and virtual environment, accessible and inclusive design overlapped in ways that made participants feel welcome and included.¹⁴ Dignity was impacted by the level of comfort, safety, and consideration participants with disability felt that a system or environment held for their interactions in that space.

Eliminating access barriers increased feelings of independence for participants, which in turn contributed to increased feelings of safety and security as well as freedom. It is important for systems-including infrastructure and environments to be designed in ways that increase independence. However, gaps between the physical experience when accessing infrastructure, between expectations and reality, and between the experience of disabled and non-disabled participants can increase vulnerability to indignity. Participants shared that physical access- uneven pathways, lack of accessible carparks, inaccessible toilets, and lack of seating increase vulnerability to undignified experiences. Additionally, prioritisation of treatment- for example policies that emerged during COVID-19, lack of interpreter services, and inability to adapt environments to individual needs, increased feelings of indignity. Most participants required a support person- paid or unpaid- when interacting and navigating systems. Support people can assist in protecting participants with disability from undignified experiences, but also highlight how access barriers require people with disability to protect their own dignity.

3.1.3 Key recommendations

1. Decisions about funding and spending must include the voices of marginalised people.
2. Co-design and collaboratively identify priorities for improving access.
3. New construction should always adhere to principles of Universal Design.
4. Retrofit old infrastructure when possible and if not feasible, seek alternative means for inclusion as outlined in the remainder of the resource.

Universal Design is an accepted mechanism for ensuring accessible and inclusive environments and spaces- virtual and physical- provide equitable access for all people. Universal Design applies to infrastructure, hard assets, signage, and other mechanisms for communicating information. It also

applies to the ways in which systems are designed to include or exclude certain people, including the use of language, the way policies are designed, and how economic priorities are defined and determined. Achieving Universal Design is often constrained by economics. Tensions may arise at the intersection between what will be funded, who benefits from the funding, and who misses out because funding is not forthcoming. Decisions made about infrastructure spending and funding must consider the perspectives of vulnerable and marginalised people who are not consistently part of discussions, if at all. Identifying priorities for changes to infrastructure and inclusive practices within a system should be undertaken, in order to accommodate the needs of as many people as possible. The research team recommends policy makers and executives undertake a collaboration with end-users, particularly those with disability, to determine the key priorities required for upgrading and improving access.

Universal Design, although essential, can be challenging. Systems have developed and endured over time, making infrastructure more immutable than the societal values that existed when it was built.¹⁵ Research participants noted multiple ways that immutable infrastructure made some places and spaces—particularly hospitals and public transport precincts, inaccessible, uncomfortable, and undignified. Newly constructed infrastructure can more readily adopt Universal Design features that support accessibility and inclusion. Retrofitting older, established infrastructure is costly and likely to be confined by space availability and legislation requirements, but is no less important.¹⁴ In instances where immutable infrastructure cannot or will not be readily changed, there are other mechanisms to support dignified experiences for people with disability, as presented in the remaining recommendations of this report.

3.2 Improve system navigation and sense-making with information

“Accessible communication is key in order to reduce and limit fear. We have many means with mobile phones and technology to utilise accessible communication to ensure dignity. Accessible communication should consider all forms of communication – audio, visual announcements, plain language and more” (DP Participant).

3.2.1 Key definitions

Access to information enables people with disability to make decisions about the ways in which they choose to engage or not engage with systems. Information can be used to sense-make and navigate a system or service as independently as possible. System navigation comprises aspects of both wayfinding and wayfaring. Wayfinding encompasses planning and deliberate prior sense-making in order to establish an expectation for how an interaction may unfold. Wayfinding is more easily controlled by people with disability than wayfaring and enables participants to be more confident and less vulnerable to undignified experiences. Wayfaring is “...concerned with the interactions between the individual and the physical and social environment”.^{16 p.647} Wayfaring comprises assessing anticipated characteristics of an interaction against an actual experience and adjusting to that experience as it unfolds, including in emergent situations. Wayfaring is more complex and uncertain, therefore increasing participants’ vulnerability to indignity. Sense-making activities cross both wayfinding and wayfaring, and thus, information is required both in advance and during an interaction with a system or service in order to better maintain dignity.

3.2.2 Key findings

Participants engaged in sense-making activities by acquiring knowledge about personally relevant experiential details, such as location of amenities, parking availability, inclusive nature of care provider, where to go, and whether they may feel safe and comfortable in interacting or engaging with a system. Most of this information was preferentially gathered during wayfinding. Research participants described the importance of inclusive, accessible, visible, transparent, consistent, and accurate information as a mechanism for maintaining dignity during wayfinding and wayfaring. Dignity was positively impacted when information was easily and independently accessible and when it could be used reliably to support sense-making. Inaccurate, incomplete, and inaccessible information

compromised dignity, increased participant frustrations and decreased confidence in interacting with a system.

Designing inclusive and accessible information for sense-making requires attention to a range of factors. Information may be gathered from websites, mobile applications, social media, staff, fixed infrastructure- including digital and non-digital signage-, by observing and interpreting what is happening, and from prior experiences. Some information is dynamic, other information changes infrequently. Particularly in the context of wayfaring, dynamically changing and emergent information must be communicated reliably and time sensitively, in order to maintain dignity. Some research participants wanted and needed to access information independently and at other times, independence was enabled if they could speak to a staff member who treated them with respect and dignity. Irrespective of where a participant is situated on the continuum of information use, dignity was impacted positively when information was easily accessible to reliably support system navigation. The challenge becomes how to accommodate the diversity of experience and requirements in the context of providing relevant and usable information for sense-making.

3.2.3 Key recommendations

1. Information should be visible, audible, and easy to understand.
2. Information should be transparent and easy to find.
3. Information should be consistent and accurate.

Common threads that participants discussed in regard to information was that consideration should be paid to visibility, audibility, language, and ease of consumption. Information should be able to be understood by participants with diverse impairments, including those with mental health and cognitive impairments. Participants with cognitive impairment expressed difficulty experienced when reading information that was not presented in plain language. The research team proposes that policymakers and system executives think critically about the following factors in regard to the design of inclusive, accessible, visible, transparent, consistent and accurate information to assist with sense-making and preserving dignity:

- Visual accessibility- is the information accessibly placed, with adequate sizing and contrast of colours to support easy reading? Signage can be both a hinderance, when not visible or accessibly presented, but also an enabler to improve navigation in a physical space.
- Auditory accessibility- is information compatible with screen readers? Are announcements easily heard in precincts or on applications and social media? Are staff speaking clearly and loudly?
- Language- is information presented in as plain of language as possible? Are there translators or translated material available? Is the person receiving the information distressed? Information presented following a health issue or a change in circumstance can compound difficulty with comprehension and retention.
- Ways in which information is communicated- is the information being communicated in multiple ways- audibly and visually, to be consumed and understood by the greatest diversity of people? Where can a person access this information- is it transparent and easy to find? How can someone reach out with questions or concerns?

3.3 Improve training and support for frontline staff

“I shouldn’t have to go up and say, ‘I’ve got crappy knees. Here’s all the scars to prove it. Please let me off the front.’ That takes away my dignity because I feel like I’m begging to be treated with respect like everybody else” (DP Participant).

3.3.1 Key definitions

High levels of empathy are based on “‘ecosystems of respect’ that permeate the entire fabric of service and social systems”.¹⁷ Systemic empathy is especially important for marginalised and vulnerable populations.

3.3.2 Key findings

Diverse perspectives and individual factors can make it challenging for systems and its staff to ensure that they are maintaining dignity for people with disability. Almost all research participants across three discrete studies mentioned staff, particularly health service staff and other frontline staff or service providers, as being critically important to retaining a sense of dignity when interacting with systems and services. Many interactions discussed by participants illuminated positive experiences in which staff supported them by treating them like any other person, particularly during help seeking or when negotiating an access challenge. Staff recognised participant’s individual impairment challenges and acted in ways that preserved dignity. Calm, respectful attitudes, talking directly to participants as opposed to their support person, and showing empathy and understanding were ways that staff upheld participant dignity. However, instances in which staff asked for intrusive and unnecessary disclosures of personal information, had attitudes that lacked acceptance and understanding, and required participants to ‘prove’ they were disabled, left participants feeling undignified and highly vulnerable. COVID-19 exacerbated many tensions with staff interactions, including making participants with disability feel like a burden or inconvenience.

Interactions with staff often occur when encountering a barrier to access, when requiring treatment and care, or other types of support. Often, participants identified that they were already experiencing a level of frustration or trepidation when interacting with staff for one of the aforementioned reasons. Relying on staff for assistance and support was problematic for many participants retaining a sense of dignity. Participants felt dependent and were placed in often unequal, vulnerable asymmetrical relationships with staff who may control outcomes, access, and information. Staff may or may not have awareness, training and education about diverse impairment and disability, increasing participant’s vulnerability to indignity.

3.3.3 Key recommendations

1. Develop environments that support staff to be engaged and empathic.
2. Address organisational pressures (time, resources, skills) to increase opportunity for staff to act empathically.
3. Identify and measure factors that contribute to empathy and respect.
4. Implement system wide empathy training, co-designed with people with disability.
5. Operationalise empathy for diverse populations.

Attitudes towards and awareness of the needs of people with disability is of critical importance when working to ensure dignity in interactions with systems and services. Failure to accommodate the needs of people with disability and undignified interactions are frequently noted. Factors that contribute to undignified interactions with frontline staff are likely to be complex and not limited to staff attitudes, awareness, and skill. Competing time and resources pressures, pandemic environment, prioritisation of services, and organisational policy all work to contribute to positive and negative interactions with staff. Staff may need to adjust their communication style to meet the needs of some people with disability; however, staff skills at adapting communication styles may vary.¹⁸ Staff are more likely to provide consistent, predictable, dignified experiences for people with disability if changes are developed together with staff training, favourable working conditions, and manageable workloads.¹⁹ If it is necessary for staff’s communication behaviour to change, then understanding the factors that constrain and enable change is also important.

Developing environments that support staff to be engaged and empathic is essential to maintaining dignity for people with disability and those who are more vulnerable and marginalised within society.

Empathy has been found to be associated with improved staff well-being and higher level of service user enablement.²⁰⁻²³

In order to achieve systemic empathy, which then influences the dignified experiences of people with disability, services and systems need to emphasize:

- identifying and measuring systemic factors that contribute to empathy and respect;
- implementing system wide empathy by learning rather than judging; and
- recognising and understanding how to effectively and efficiently operationalise system wide empathy across diverse populations.²⁴

This can be done by engaging more fully with human experience.¹⁷ Fully engaging with human experience is facilitated by including service-users in consumer leadership that facilitate transformative change and regenerative solutions to improve dignity experiences.^{9,25}

3.4 Create spaces for voice, choice, and independence

“Dignity is making sure my wants and needs are respected and I’m not treated like some inspiration or burden” (DP Participant).

3.4.1 Key definitions

Disability and impairment is not experienced homogenously by all people with diverse impairments nor by those with the same types of impairment(s). Intersectionality- factors like gender, culture, socio-economic status, multiple impairments, religion etc. contribute to identities which in turn, impact on the different personal factors that affect dignity. Disability, in the context of this research, is grounded in the *United Nations Convention on the rights of Persons with Disabilities* and is conceptualised as resulting “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”.²

3.4.2 Key findings

Recognising the diversity of impairment and disability increases comfort, security, and feelings of respect for people with disability when interacting with systems and services. Participants across all three studies discussed the heterogeneity of lived experiences and the desire for systems to provide flexible service and care provision, based on individual preferences, rather than medical diagnosis or assumed functional requirements. Providing opportunity for participants to express their individual preferences can prove challenging and time consuming for systems, particularly for staff tasked with organisational imperatives and resource pressures. However, creating space for open discussion and recognition of preferences decreases vulnerability to undignified interactions, experiences and outcomes.

Participants closely related dignified interactions with systems and services with the opportunity to express agency through voicing of preferences and independent (albeit supported) decision making. Opportunities to enact choice and independence increased feelings of safety, security and dignity for participants. Participants particularly expressed the desire to articulate preferences surrounding help seeking, controlling for the ways in which they want to be helped, how they want to be helped, and when they want to be helped. Voicing preferences for assistance and support enabled participants to feel more in control and increased feelings of dignity.

3.4.3 Key recommendations

1. Create opportunities for people with disability to express their preferences.
2. Embed opportunities for choice and agency in policy and procedure to support staff engagement.
3. Regularly review preferences and choices to respond to fluctuation in impairment and capacity.

4. Co-design system change, policies and procedures with people with disability.

Creating flexible services that respond to the preferences and choices of people with disability is a critical challenge, but one worth working towards, as it can result in more dignified interactions and outcomes. The historic erasure, dismissal, silencing and patronising of people with disability as the authority of their own experience and care, particularly in health service settings, must be addressed in order to increase dignified experiences and interactions. Embedding opportunities for people with disability to express choice and enact independence should be implemented across policy and procedure. Activities similar to the palliative care Patient Dignity Question, which asks, “*What do I need to know about you as a person to give you the best care possible?*”⁷ should be examined, implemented, and regularly reviewed, to reflect continuity of care but also the fluctuation and changing of preferences and capabilities.

Policy and procedure change to embed space for expression of voice, choice, and independence will be bespoke and consider the organisational constraints and factors of each system or service. However, embedding the voices of lived experience into the development of new policies is integral to maintaining dignity throughout. Community consultation and undertaking co-design of system change is imperative in order to better understand the system specific barriers that limit voice and choice, while ensuring that new procedures account for heterogeneity of lived experience. Embedding the voices of lived experience into service design and delivery will enable systems and services to protect and increase the proliferation of dignity throughout holistic service engagement for people with disability, in a manner that is sustainable and authentic.

Conclusion

Most of us have had experiences in which we felt somewhat disrespected; transactional encounters that fail to recognise our full humanity. Many of us simply shrug this off. We understand that people are busy and sometimes unintentionally inattentive. We appreciate that within large bureaucratic structures people are driven by processes and policies and not always by relationships. We may sigh or swear with frustration, but our lives are not too disrupted. The experience of people with disability is different. Casual indifference can precipitate marginalisation. Indeed, for many people who grapple with impairment and vulnerability, such instances have grave implications, creating risks, barriers to access, and threats to wellbeing, even life. It is within our control and capacity to reverse this tendency and avoid such outcomes.

Dignity is a powerful framing device to this end. The term calls to mind a deeper reverence and respect for the value of everyone. When the term is considered in tandem with disability it serves as a reminder that impairment should not forestall moral consideration. Indeed, the fact that people may have impairments also means that respecting their dignity requires specific consideration so that all people can interact with and participate in the social systems, like hospitals, that are designed to provide care and support.

Our research has uncovered four core strategies that will help ensure that individual encounters in complex systems are dignified. More than this, however, these strategies will help design the very system- places, programs, and policies- which will support dignified encounters and experiences. The four steps you need to take are:

1. Eliminate or minimise access barriers through the use of Universal Design.
2. Improve system navigation and sense-making with information that is accessible and inclusive.
3. Improve training and support for frontline staff to create cultures of empathy and dignity.
4. Create spaces for the expression of voice, choice and independence for people with disability.

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Appendix A: Study 1

Study Title: Dignity Project Part 1: Citizen Science in Disability and Rehabilitation

Funders and partners: Queensland Office of the Chief Scientists and Motor Accident Insurance Commission (MAIC)

Aims: Uncover how dignity is experienced, understood and defined by people with disability, including barriers and enablers across systems and services in order to improve inclusion and participation. Additional aim was to develop an online solutions and community building platform for people with disability, called the Community Hub.

Methods: Mixed methods, qualitative study using an bespoke approach to extreme citizen science, co-designed by researchers and people with disability. Phase 1 of the research consisted of an online survey, delivered over two time points (July and November 2020). The survey supported participatory research using digital storytelling mechanisms to uncover citizen data. Phase 2 consisted of two virtual focus groups accompanied by a demographic survey as a solution building mechanisms for uncover strategies for promoting dignity in practice. Framework Analysis (Ritchie & Spencer, 2002) was utilised to analyse data systematically and thematically. Recruitment occurred through the Dignity Project Community Hub.

Participants: Seventeen participants completed the online survey in phase 1 and five participants engaged in the two focus groups (n=3 participated in both phases). Participants were predominantly female (59% and 60% respectively for phases 1 and 2). Most participants identified as having a physical impairment (53% and 80% respectively).

Results: Results of this study uncovered the central importance of the acknowledgement of people with disability to the protection and maintenance of dignified experiences. Health systems and services were uncovered as the first system within which people with disability experience vulnerability to indignity, particularly for people with acquired impairment. Employment systems and public transport were also identified as critical systems in which vulnerability to indignity was frequently experienced. Dignity for people with disability is predicated on acknowledgement of worth and value, existence, and embedded practices of accessibility and inclusion in system and service design. The importance of frontline staff in systems and services to the outcome of dignified experiences was discussed by all participants.

Community Hub: The Community Hub currently has 110 members with diverse lived experience of disability and impairment. The Hub conducts regular online forums and digital storytelling opportunities as a mechanism for building research awareness and capacity, driving research agendas, and facilitating change.

Appendix B: Study 2

Study Title: Dignity Project: Understanding the interaction between mobility possibilities and freedom of movement for people with disability

Funders and partners: The Department of Transport and Main Roads

Aims: Uncover how people with disability choose or choose not to interact with public transport and how dignified mobility experiences are supported or impacted.

Methods: The study was completed over three qualitative phases (1) in-depth interviews with people with disability, (2) ride-along and precinct observations with participants in phase 1, and (3) persona development and testing through focus groups.

Participants: Discussion of participants and results is limited to phase 1 only, due to ongoing confidentiality agreements. Twenty-six people with disability completed semi-structured interviews as part of phase 1. Participants identified as female (50%), male (46%) and non-binary (4%). Participants were able to identify multiple impairments, resulting in 18 identifying as having an invisible impairment and 17 with visible impairments. The majority of participants (80.7%) identified as having a physical impairment.

Results: This study validated the findings from study 1 and further uncovered the critical importance of accessible and inclusive information, to enable independent navigation of systems. Independent system navigation and controlled interaction with systems increased participant dignified mobility experiences. Universal Design emerged as important for dignity, although implementation proved challenging and inconsistent in practice. Finally, the importance of frontline staff attitudes and interactions was re-iterated by all participants in this study.

Appendix C: Study 3

Study Title: The Dignity Project: understanding the impact of COVID-19 on Australians with disability

Funders and partners: Motor Accident Insurance Commission

Aims: Uncover the impact (both positive and negative) of COVID-19 on the physical, emotional and mental health of people with disability in the Dignity Project Community Hub. Understand how dignity may be impacted through changing employment, increased social isolation, and reliance of new technologies.

Methods: Online Likert-type survey with qualitative free response sections, run through the Community Hub.

Participants: Twenty-two participants completed the online survey. Participants identified primarily as having physical impairment (29.55%) and cognitive impairment (25%), although each participant as able to identify multiple impairments, most of whom did so. Most participants identified as female (68%).

Results: Participants with mental health impairments reported the most negative impact of COVID-19 in relation to their emotional wellbeing, ability to work and overall financial situation. Participants with hidden impairment reported higher rates of negative impact of COVID-19 on their emotional well-being, financial situation, access to medical treatment, social interactions and ability to work. There was correlation between participants who were casually employed and higher reported levels of negative impact, particularly for female respondents. Participants identified that COVID-19 and the associated public health measures presented barriers to dignity, particularly around the prioritisation of life saving health services and the quality of telehealth technology. The lack of recognition of the importance of people with disability and the attitudes towards “quality of life” resulted in participants feeling undignified. Telehealth and technology, when accessible and inclusive, increased feelings of dignity.

Appendix D: ongoing Dignity Project Research

Dignity in HabITec: barriers to accessing smart technology for people with disability

Funders and partners: Motor Accident Insurance Commission

Aims:

Methods:

Dignity Project: understanding patient perspectives on dignity in the rehabilitation context to improve satisfaction

Funders and partners: Gold Coast Health Collaborative Grant Scheme, Gold Coast Hospital and Health Service

Aims: Uncover patient and staff perceptions about the barriers and enablers to dignified care in rehabilitation settings in order to co-design workable solutions to support dignified care for people in rehabilitation.

Methods: Generative co-design approach (7 steps) including semi-structured interviews with patients with lived experience of rehabilitation and rehabilitation staff; co-design focus groups; capacity building workshops.

First Peoples and Rural and Remote Community Recommendations for Improving NDIS Plan Utilisation in Queensland

Funders and partners: Queensland Department of Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships

Aims: Develop recommendations for improving NDIS plan utilisation, based on the experiences and insights of Queensland First People and people living in rural and remote communities.

Methods: Mixed qualitative methods facilitated through the Dignity Project Community Hub (online platform) including: online survey, focus groups, and interviews.



The Dignity Project

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