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Unheard voices.

11th Inclusive Design Conference
Helen Hamlyn Centre for Design

Conference Proceedings (Online)

Royal College of Art, London, UK
22-23 September 2022

Royal College of Art
THE HELEN HAMLYN CENTRE FOR DESIGN

INCLUDE. Unheard Voices is a global conference that focuses on inclusive design and its people-centred, creative approaches. It is hosted by the Helen Hamlyn Centre for Design at the Royal College of Art.

The Helen Hamlyn Centre for Design (HHCD) is a globally recognised centre of excellence with a 30-year history of applying inclusive design and design thinking to improve people's lives. The term 'inclusive design' was framed by HHCD's founding co-director Roger Coleman in 1994, as a people-centred, comprehensive and integrated design approach to ensure that people with diverse abilities and needs are included in mainstream design consideration for products, services, technologies, and environments. The HHCD is the largest and longest-running design research centre of the Royal College of Art (RCA). The RCA was established in 1837 and in 1967 was granted Royal Charter and University status. It is a wholly postgraduate university institution of art and design, offering MA, MPhil and PhD degrees, and to this day, remains the world's leading university for art and design education, having received the #1 QS Ranking for the eighth consecutive year since 2015.

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Age Inclusive Digital Platforms

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As services increasingly shift online, older people need to utilise more digital technology. However, many digital platforms still lack the inclusiveness required for all older people to use and engage with them. Some using technology frequently meet a digital world unsuited to their cognitive, sensory, functional and socio-emotional abilities. So, their digital experience seldom aligns with their digital literacy, or personal wants and needs. As most digital platforms are not designed for older people, they are more likely to require assistance to use them. This can impact financial resilience, health, and sense of belonging. To encourage platform developers to utilise an inclusive design approach, to better consider the needs of older people, we created guidance for developing age-inclusive digital platforms. This involved focus groups, interviews, and user testing. We analysed older peoples' use cases, interviewed development teams and reviewed best practices worldwide. This resulted in a Hebrew-language booklet for developers and designers, which we recently translated to English. With initial adoption, we are starting to see these principles implemented in Israeli government and municipal digital services. We hope to create further meaningful change in the usability of digital platforms to improve the lives of older people, including our future selves.

Keywords: *user experience; inclusive design; older people; digital*

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Introduction

Globally the 65+ age group is expected to increase from 9% in 2019 to 16% by 2050, more than doubling from 727 million to 1.5 billion (UN, 2020). These older people are adopting technology more than ever before. So, the Internet, smartphones, tablets, wearables, smart TVs and speakers are being used by a growing number of older people. During the Covid-19 pandemic, this trend became even stronger. In the UK, 54% of people 55+ have been using more online services since the start of the pandemic, with 17% signing up to at least three new online entertainment, socialising, or shopping services (Santander, 2020). Older people are increasingly motivated to use digital technology, for example, 38% of older Americans recently described the Internet as essential (Pew, 2021). However, many older people still lack Internet connectivity or the skills to use technology, in a way that would enable them to consume digital services. It was recently determined that 22 million older Americans are still not online. With people 75+ particularly likely to say they need help with new devices. With 66% saying they usually need help setting up a new computer, smartphone, or other electronic devices, compared with 48% of those aged 65 to 74 (Pew, 2021). This and other challenges lead to less usage of digital platforms. In Israel, the underutilisation of basic digital services by older people (65+ years old), compared to younger people (20-65 years old), is well documented, as summarised in Table 1.

Table 1. Social Survey 2020: The percentage of younger and older people that make use of basic digital service types - summarised from (Central Bureau of Statistics, 2020)

	Search for information	E-mail	Banking and paying bills	Shopping or online services	Online government services	Social media
Younger People (20-65)	**77%**	**77%**	**68%**	**52%**	**52%**	**90%**
Older People (65+)	**55%**	**46%**	**37%**	**20%**	**26%**	**69%**

This difference demonstrates the broader problem of the Digital Divide, when different groups in society have different levels of access to digital technology (Cullen, 2001). While the inequity of the Digital Divide begins with differential access, it leads to inequity in opportunities for economic mobility and social participation (DiMaggio *et al.*, 2004). This can have major impacts on mental and physical health, as well as their ability to function in and contribute to society. Therefore, overcoming the Digital Divide, with regards to age, can improve labour opportunities; economic efficiency and productivity; ease of activity, connection and leisure; ability of individuals to access health services and other public services; etc (Khvorostianov, Elias and Nimrod, 2012). The challenge is not only to empower older people by providing access to digital technologies and enhancing digital literacy, but to ensure age-friendly design and relevance of digital services that embrace the diversity of ageing populations. Currently, many digital platforms do not meet the needs and abilities of older people. For example, it was reported that 40% of older people feel that the design of technology does not consider them

(Kakulla, 2022). Furthermore, older people are twice as likely to abandon a digital task than younger people, and 30 seconds earlier than their younger counterparts (Petrovčič, Rogelj and Dolničar, 2018; Chisnell and Redish, 2005). While accessibility requirements assist with the challenge, they generally do not exhaust the usability potential of digital platforms. For example, many sites and apps satisfy accessibility criteria, but then fail usability tests (Petrie and Kheir, 2007). So, the focus should be on improving usability to close the gap left by accessibility requirements (Johnson and Finn, 2017). Some older people suffer from cognitive, socio-emotional, and sensory changes that affect the way they perceive and use digital platforms. Compared to younger users, they may perform worse on tasks that require memory, be more easily distracted, require more time to study new tasks, use different search strategies, and make more mistakes or perform more random actions (Bergstrom, Olmsted-Hawala and Jans, 2013).

The remainder of this paper is organised as follows. The next section (2) considers the study design for developing the design guidance for age-inclusive digital platforms. The following section (3) presents the results, and the final section (4) discusses the conclusions.

Study Design

Introduction

The Joint Distribution Committee (JDC) is a global Jewish humanitarian organisation. The goals of JDC Israel, also known as The Joint, include promoting quality of life and equitable opportunity, narrowing socioeconomic inequities. One of their programmes is the Digital Literacy for Older Adults initiative, in partnership with the National Digital Agency, which has operated over the past four years. It aims to put technology in the hands of older people to achieve meaningful outcomes, empowering them in their personal lives. The initiative is achieving its goals by improving digital literacy through training; providing tablets and Internet connectivity to those with decreased functional ability, economic difficulties or that are homebound; and providing the tools, knowledge and best practices for age-inclusive digital platforms. Thus far, more than four thousand older people and one thousand professionals have been trained.

A number of principles have been formulated for designing and adapting digital platforms to include older people. Some include the issue of accessibility and relate to the areas of universal, inclusive and person-centred design generally. While others include aspects unique to older people, which originate from psychosocial features and low digital literacy levels. We aimed to consolidate this existing knowledge and make it more accessible to professionals to improve usability in practice. Providing them with best practice and practical tools, to ensure their digital platforms are inclusive, especially age-inclusive.

The translation of the guidance to English was done in collaboration with the Royal College of Art (RCA), which will be described further in subsection 2.3. The RCA has a long history of Inclusive Design, dating back to the 1990s, where Coleman and colleagues introduced this then new approach to design for ageing. In which, it was essential to move beyond considering ageing as just bodily needs and medical decline, instead, considering people's lives holistically when designing (Coleman, 1994; Clarkson and Coleman, 2015). An integral part of the programme consisted of training future designers, i.e. design students, to engage with older people through inclusive design.

Methodology

We conducted a literature review including (Morey *et al.*, 2019; Silva, Holden and Jordan, 2015; Lee and Coughlin, 2015; Petrovčič, Rogelj and Dolničar, 2018), as well as non-academic literature such as (Kane, 2019). We consulted a focus group, 8 participants aged 65-80, who were asked for their feedback on a set of examples with regards to the User Experience (UX) design. We also conducted usability testing for a small number of essential digital public services, including healthcare, banking, email and local municipalities. These were done with 8 participants, both male and female, aged 65-85, who had low to medium digital literacy, for which the main challenges were observed and documented. We also conducted 20 in-depth interviews with leading Hebrew speaking industry UX professionals and academic researchers. Integrating the literature analysis, participant feedback (frequency of comments, and criticality of elements to complete tasks) and expert interviews, we identified the five most critical issues for developing digital platforms to increase usability for older people:

1. visual aesthetics
2. wayfinding, navigation and information architecture
3. microcopy and UX writing
4. flow, friction and feedback (navigation)
5. motor aspects (interface operation)

We subsequently organised 5 learning groups in response, with UX professionals and academic researchers recruited through open invitations on social media. For the 112 who responded, we divided them across the learning groups according to their experience of digital platform development for older people. So, there were a similar number of those with different levels of experience in each group. They were asked to share their experiences with usability testing and best practices, as well as examples of failure and success. An older person was invited to join each group, to contribute their own perspectives. Five meetings were held in total, one for each group, which were recorded and analysed, grouping the main insights into key themes. Subsequently, 20 key participants from the learning groups were asked to join our existing expert group, of UX professionals and researchers, in validating our guidance. They were asked to comment on the structure of the guidance and chapter content, as well as the accessibility and usefulness of the guidance itself.

Subsequently, the Hebrew guidance was translated to English to reach additional audiences. This was assisted by collaborators based in the field of Inclusive Design, ensuring that the intended inclusiveness remained in the translation. The translation of the language and culture is described in the next subsection 2.3.

Translation

Cultural translation is the practice of translation while respecting and acknowledging cultural differences. As culture gives birth to language, translation and culture are intimately connected. Meanings in both source and target languages are profoundly affected by their cultural context. A phrase that appears easy to translate may actually contain cultural subtleties that, unless they are accounted for, can bring just the opposite meaning than is intended. So translation without deep cultural context can be dangerous, especially when meanings are critical (Carbonell, 1996; Aixelá, 1996). Translation plays an important role of crossing through different cultures and communication. Therefore, it is one of the essential, fundamental, and adequate ways of transferring culture, but there are some limitations, including censorship and even culture itself. So, a good translation should simultaneously be aware of the cultural factors, such as views and tradition, to consciously consider the

chronological ordering and explicit meaning, as well as historical and cultural background contexts (Abbasi, Hossain and Owen, 2012).

In practice, our language and culture translation involved a first stage by a native Hebrew speaker, who spoke English as a second language, which was primarily language translation. Then, a second stage, by native English speakers, which was primarily cultural translation. This stage involved determining the typical terminology in context, changes from writing orientation, as well as American and British language differences. For example, when referring to online services and websites, the typical terminology is digital 'platforms' rather than 'products'. The American and British language differences were more nuanced, especially when considering an international audience, and beyond spelling differences. While American English may be globally dominant in terms of spelling, British English terminology regarding smartphones is globally dominant. For example, the word 'mobile' or term 'mobile phone', rather than 'cell' or 'cell phone'. There were also potential cultural differences regarding intergenerationality and technology adoption that had to be considered.

Results

The guidance was divided into 5 chapters, corresponding to the required stages in digital platform development (Halperin Ben Zvi, 2021). Each chapter presents a true story demonstrating an issue in the lives of older people using digital platforms, which is followed by an explanation of its significance and guidance for managing it. The guidance also provides information regarding the changes that occur with age, and their implications for the behaviour of older users.

Information Architecture, Orientation & Navigation

As age increases, sometimes, the speed of information processing decreases, taking longer to absorb, comprehend and perform certain actions (Anstey and Low, 2004). Also, many people aged 65+ find it difficult to ignore distractions, and are more prone to perform random actions, including unintentional clicking. Some feel insecure and unable to orientate themselves within digital environments. Therefore, inclusive information architecture principles should be observed when designing digital platforms, with the main guidance for designing better information architectures and hierarchy formation as follows:

- refine the required actions and include shortcuts
- rely on recognition to ease navigation:
    - allow going back
    - design clear navigation buttons
    - remain consistent, and provide hints for their location (within the process)

Microcopy & User Experience Writing

Many older people rely on the written word of digital platforms, usually reading more carefully than younger people, who rely more on usage habits and familiarity (Fan, Zhao and Tibdewal, 2021). Therefore, text should be concise and well placed throughout the user journey to strengthen a sense of success and capability. For example, clear articulation of error messages, including instructions for repair actions, strengthens the sense of efficacy for older (and younger) people. This is because it helps them cope with uncertain situations, reducing the risk of

abandonment. The following guidance helps with writing microcopy and design messages to provide high usability, allowing older people to enjoy using it successfully (as demonstrated in Figure 1):

- Direct ‘down-to-earth’ writing - familiar words, with clear and simple phrasing.
- Add dialogue messages and success feedback, especially during uncertainty in the user journey, including reassuring notifications upon successful actions.
- Accurate and clear error messages with a call-to-action - explaining the type of error in plain language, and providing a choice between responses, including explicit instruction for a solution and the call-to-action.
- Control the rate of progress when possible, best avoid messages (pop-up/toast) that appear and disappear on their own. Instead, allow the user to confirm or cancel action.

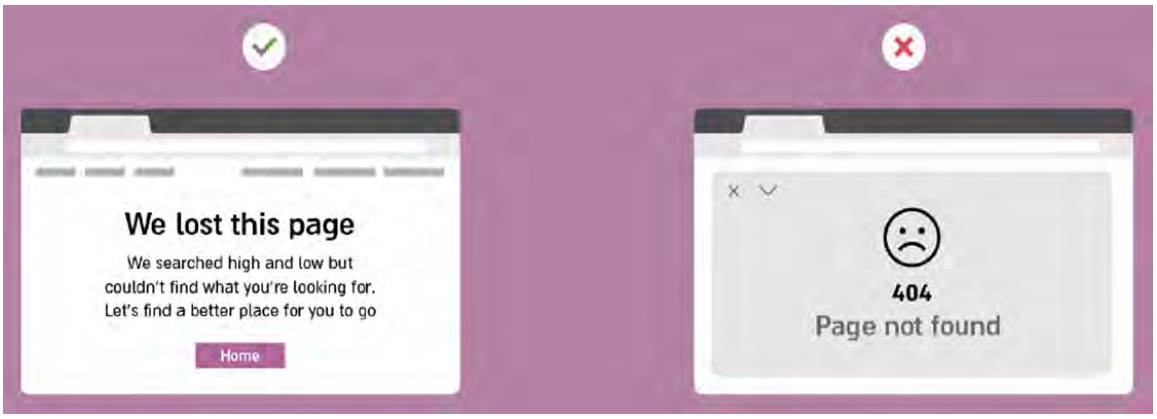

Figure 1. Example Microcopy & UX Writing Guidance: A better design for the common 404 error

User Interface & Design Decisions

Many older people experience decreased eyesight (Freeman *et al.*, 2007), including difficulties seeing up close (age-related farsightedness), as well as differentiating between certain colours and the hues of a colour. Also, many do not use accessibility add-ons and do not change device settings, which can make usage much easier. So, a good choice of colours, fonts, and size of objects allows older users to use digital platforms more easily. We have developed 6 simple principles to follow, building upon the WCAG accessibility standards (W3C, 2008; 2018). Implementing these principles at the early stages of digital platform design will help older and younger people with visual impairment:

1. Choose font size and spacing, which makes it easier to identify letters and read (preferably Sans Serif).
2. Maintain high contrast.
3. Large, well-spaced objects, ensuring operation does not require fine gestures and accuracy.
4. Deliver information through colours, but adding icons to not rely solely on colour to mark actions.
5. Use pictures and icons similar to their real world counterparts, and add text tags to icons where possible.
6. Provide salient and clear information regarding invisible expandable components.

Forms, Registration & Sign-in

Changes may occur with age, affecting memory and the ability to plan, execute, and delay response (executive functions) (Anstey, 2004). Filling many details into forms and creating passwords (especially hard to remember ones) is tedious for all, even more so for older people. Therefore, when designing fillable forms, we recommend examining their necessity and whether to remove them. If unavoidable, they should be simplified as much as possible, making it easier for older people. We recommend writing a short explanation about the necessity of registration when required, and reducing the number of fields, designing them to be user-friendly, as demonstrated in Figure 2.

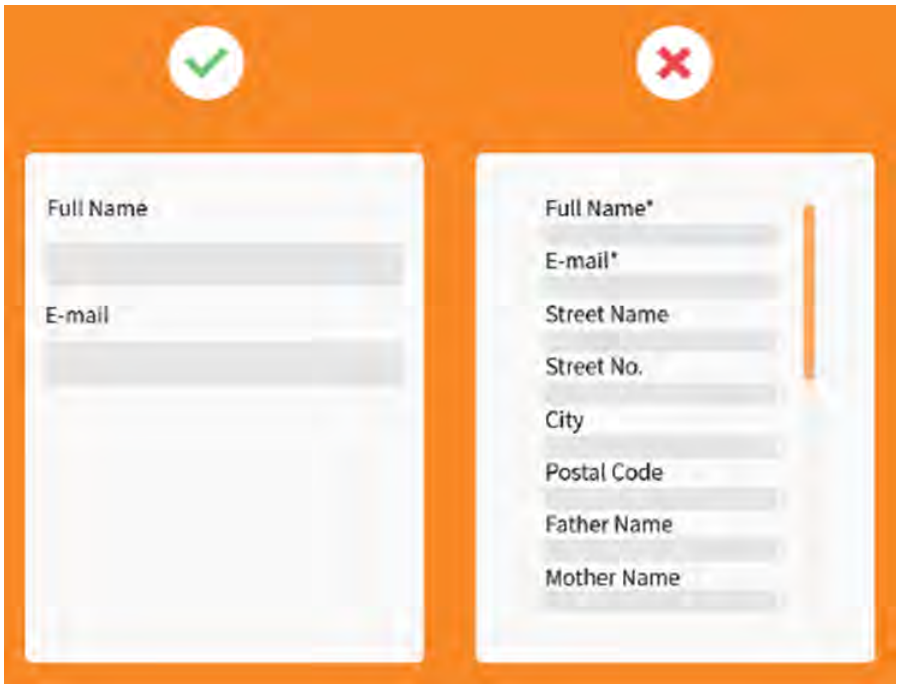

Figure 2. Example User Interface & Design Decisions Guidance: A better design for user registration

User Research

To enhance the adoption of digital platforms by older people, it is highly recommended to use UX research methods, including user testing and usability testing (Mannheim *et al.*, 2019), throughout the development process. Not only to examine existing digital platforms, but also in developing new ones. When planning user research, it should be noted that the older age group is highly diverse; spreading potentially over 40 years with greater in-group differences than any other. So, avoid ageism when recruiting, and prevent self-ageism as follows:

- Avoid mentioning participant age and referring to limitations/disabilities characteristic of their age group.
- Ensure clarity by providing clear and accurate instructions to reduce stress.
- Provide feedback to participants where possible, as to whether their comments were considered.
- Ensure fairness and ethical standards, with short and simple consent forms.
- Ensure accessibility, including with user devices and physical environments.

Conclusions

The challenge of equity in the Inclusive Design of digital technologies, includes unfriendly (exclusionary) design and functional irrelevance for older people, which can then become barriers to use. The design of interfaces typically does not address the requirements for a diverse range of users, failing to meet criteria for accessibility, usability and inclusivity. This can negatively affect older people, particularly those with physical or cognitive disabilities. Design processes often occur without the input of all end users, because of preconceived judgments regarding who will use specific digital technologies (UNECE, 2021). When digital technologies are specifically designed for older people with disabilities, it typically reflects the ageism of designers - their implicit stereotypes about 'the older technology user'. Instead, we need inclusive, age-friendly design in the development of mainstream digital technologies (Rothwell, 2017). This would ensure economies of scale, as well as widespread social acceptance of the enabling digital technologies, minimising the potential for stigmatisation.

The limitations of this work includes a lack of empirical confirmation that following the guidance will increase usability, and whether this would be through greater engagement and/or retention. Also, whether detailed instruction, rather than broader guidance, may be required for certain challenges, such as payment issues. Building upon our approach of involving multiple stakeholders in collaborative efforts, there should be greater collaboration between academia, industry, government, third sector, and older people. This should include case studies reflecting on the effectiveness of applying the guidance to digital platforms. This could include banking, online shopping, leisure, sports, and lifelong learning. Over the next two years, our goal is to implement the guidance in two different ways. First, working with major organisations to improve their digital platforms with the guidance, testing changes in use by older people. The first three are MOOVIT (most used public transportation app in Israel), Clalit (largest healthcare provider in Israel) and Ashdod municipality (as an exemplar of better serving older residents). Second, increase awareness among designers of digital platforms by incorporating the guidance into the syllabus of higher education institutions; and informing professional designers how to make use of guidance through conferences, webinars and publications. This aims to ensure that future designers are aware of age-inclusivity, and therefore included in the design of future digital platforms to improve usability in practice.

The coronavirus pandemic identified broad socio-economic challenges, and acutely how the lack of digital usage can increase isolation, affecting both mental and physical health. It showed worldwide that participation in digital platforms could mitigate feelings of social exclusion in times of physical distancing (Seifert, 2020). The pandemic highlights the importance of the usability of digital platforms for improving the lives of today's older people, and our future selves. We hope that the guidance, along with change in awareness, will lead to greater inclusion.

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Towards the Inclusive Design of a Digital Sexual Health Promotion Programme

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Designers creating products to promote sexual health find little guidance to make their products inclusive, especially considering the stigma associated with taboo subjects and cultural associations with sexuality and intimacy. To overcome this limitation, we used mixed methods to inform the design of a smartphone app to deliver a sexual health promotion programme to older adults and their partners, also including colorectal cancer survivors as an extreme user group. Our findings pointed towards the relevance of app behaviour and, thus, led us to conceive of the app as an agent. Therefore, we suggest the concept of *Rules of Etiquette* to complement prescriptive design pattern and function guidelines. At a time when digital interaction becomes growingly dematerialised, identifying behaviour rules may be more appropriate for intangible interaction than traditional guidelines alone and a promising way to pursue inclusive design around sensitive topics.

***Keywords**: design research methods; sexual health; mHealth; ageing*

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Introduction

Although sexual health is an important component of wellbeing and quality of life, older adults and people with chronic diseases are often still barred from experiencing a positive, healthy, and fulfilling sex life (Smith *et al.*, 2019). Smartphone apps can be a suitable vehicle to promote sexual health among these user groups. They are intimate and ubiquitous objects which can avoid the stigma of seeking personal sexual help, motivate engagement, and help overcome geographical barriers to getting sexual health support. Although older adults are often associated with low digital technology use, this age group has been steadily increasing its access and use of digital technology, such as the Internet (Hunsaker and Hargittai, 2018).

To be inclusive, such technology should welcome diversity beyond age and digital literacy, accommodating a spectrum of gender identities, sexual orientations, sexual behaviours, and relationship arrangements. It should allow being used by people with or without sexual partners.

Inclusive Design advocates for the inclusion of diverse users in the design process, including extreme users (Dong *et al.*, 2005). However, when it comes to sensitive or taboo topics, literature is scarce on guidance about how to deliver inclusive designs. Behaviours and attitudes towards sexual health also vary greatly depending on the culture (Sinković and Towler, 2019). Therefore, inclusive design applied to the topic must be culturally sensitive as well.

Drawing on our experience in a multi-partner European project developing a smartphone-based programme to promote sexual health among older adults, including those with chronic disease, we suggest that inclusive design guidelines can be about technology behaviour and not just about product/interaction design features.

Related work

Despite its relevance, inclusive design for sexual health has been underexplored. Researchers' work with sensitive or taboo topics, such as menstruation or sexually transmittable diseases, has not so much led to design guidelines as to researchers' reflections about going about codesigning. Examples are using humour, enabling safe spaces, using fictitious scenarios or creating embodied experiences (Almeida *et al.*, 2016; Wood, Wood and Balaam, 2017).

Research in inclusive design has sought to identify general guidelines for inclusive products and spaces (e.g., Mace, Hardie and Place, 1991; Abascal and Nicolle, 2005; Kascak, Rébola and Sanford, 2014). It has tried different approaches to help designers adopt inclusive design through calculating exclusion (Waller, Langdon and Clarkson, 2010) or sharing methods to design with extreme users (Dong *et al.*, 2005). Gender is also growingly problematised as a relevant dimension of inclusive design (Weixelbaumer *et al.*, 2014; Burtscher and Spiel, 2020).

Regardless of the focus, papers group around 1) raising awareness among designers about inclusive design, 2) providing tools to create inclusive designs, and 3) providing tools to design with a wide diversity of users. We aimed at contributing to no. 2.

Methods and participants

We used mixed methods to identify design principles for the design of a smartphone app to deliver a sexual health promotion programme (that can be thought of as a self-help course) for older adults, people with chronic disease and their partners in different European countries. We began by trying to capture unmet needs and gradually moved into specific aspects.

Our study received ethical approval from the ethics committee of the oncology hospital IPO-Porto. Informed consent was obtained from all participants before each procedure.

The study had two large phases: Phase 1 to elicit design requirements and Phase 2 where we conceptualised and pre-tested rules towards inclusive app behaviour. The activities from Phase 1 are listed and numbered in Table 1. Each line describes activity, purpose, participants, and countries involved.

Table 1. List of activities used in Phase 1

Activity	Purpose	Participants	Country
1. Archetype exploration	Create provocative archetypes to foster reflection among the design team	Consortium (designers, engineers, sexologists)	Portugal, Netherlands, Kosovo, Norway, Austria
2. Couple interaction exploration	Create speculative designs about how sexual couples could use the app simultaneously	Design team	Portugal
3. Online questionnaire	Understand unmet needs and attitudes towards a sexual health promotion app	1.119 older adults	Netherlands
4. In-person Workshop	Understand: - barriers and facilitators to using the app - appropriate tone of voice for the app - preferred mode of delivery - design components contributing to trustworthiness	6 older adults	Netherlands
5. Online questionnaire	Validate: - tone of voice for the app - preferred mode of delivery - design components contributing to trustworthiness	111 older adults	Netherlands
6. In person workshops	Understand appropriateness of anatomical illustrations	9 older adults	Netherlands

7. In person workshop	Understand appropriateness of anatomical illustrations Assess text usability and perceived cognitive load	4 older adults	Portugal
8. Usability tests	Understand appropriateness of anatomical and medical device illustrations	4 older colorectal cancer survivors 4 healthcare professionals	Portugal

Results from Phase 1

In this section we provide the results obtained with each activity and, where relevant, these results are intertwined with discussion and/or implications for design.

In **Activity 1**, before getting ethics approval to engage with users, we created individual and couple archetypes based on a literature review and the *Genderbread Person* (hues, no date). Each archetype had a fictitious scenario (Figure 1). These materials were used in co-creation workshops with the consortium and allowed to explore implications of different combinations for design features, content, and app navigation. Through this exercise, we became aware of the importance of addressing sexual fluidity and accommodating the needs and realities of extreme users and couples. These findings set the tone for subsequent explorations.

Based on a list of couple exercises usually prescribed by sexologists, we created a set of speculative designs (**Activity 2**). In these designs, we explored how the communication and geolocation of smartphones could be used to instil users to engage in the exercises and to augment the proposed activities. We concluded that exercises imposed the presence of a smartphone, like a third party between the couple. We wondered how users would react to sexually charged notifications and whether they would be embarrassed to have them on their phones. We questioned which role aesthetics would play between being sufficiently discreet, while simultaneously engaging and provocative. Here, the thought of the app as an agent (Latour, 1992) started taking form.

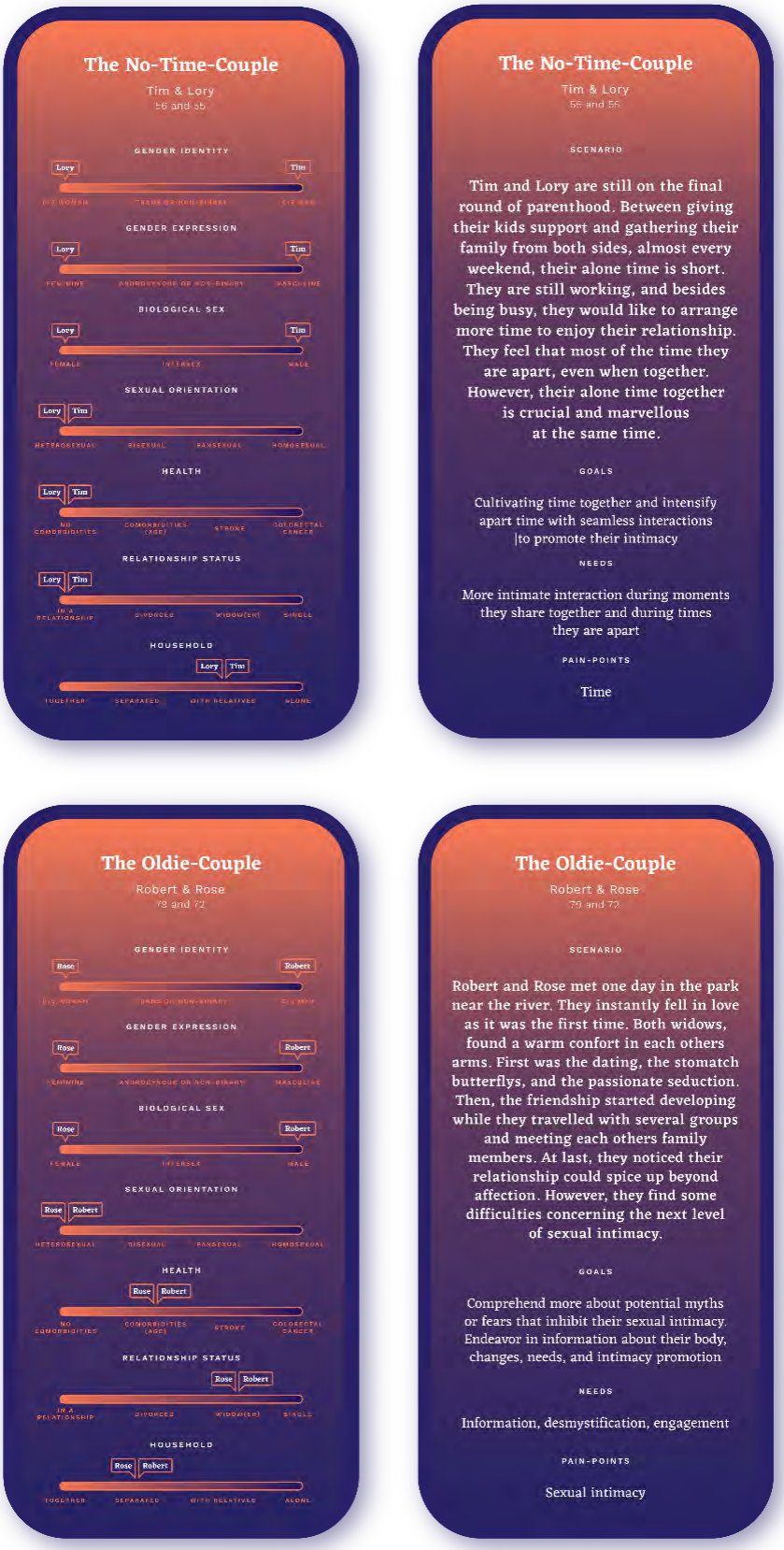

Figure 1. Examples of archetypes and scenarios

Figure 2. Explorations of smartphone-smartphone exercises

With the questionnaire in **Activity 3**, we learned that men engaged more in our user research and were more willing than women to use an app such as the one we intend to create. We learned that among respondents (all over 55 years of age, mean age 74) many were sexually active, but roughly ¼ experienced an impairment that interfered with sexual activity. We learned that users are wary of the Internet to look for reliable information on sexual health. Finally, through qualitative analysis of open-ended questions, we learned that people need advice, need information, and might also just need a listener.

Accordingly, we understood that the app needed to be highly trustworthy, and we ran an in-person workshop (**Activity 4**) to explore various aspects of trustworthiness. We began with an overview of questionnaire results from Activity 3, which motivated a discussion into barriers and facilitators of app use. Following the discussion, we presented participants with sets of cards resembling smartphone screens to remind participants at all times that the workshop revolved around a future app. Based on an example by NN/g (2016), the first set of cards presented the same information about the programme and its modules, but using different combinations of tone of voice (Figure 3). Using two different screens, we also probed whether having hidden information, in this case, button labels, would affect trustworthiness (Figure 4).

Figure 3. Four images used for the tone of voice exploration

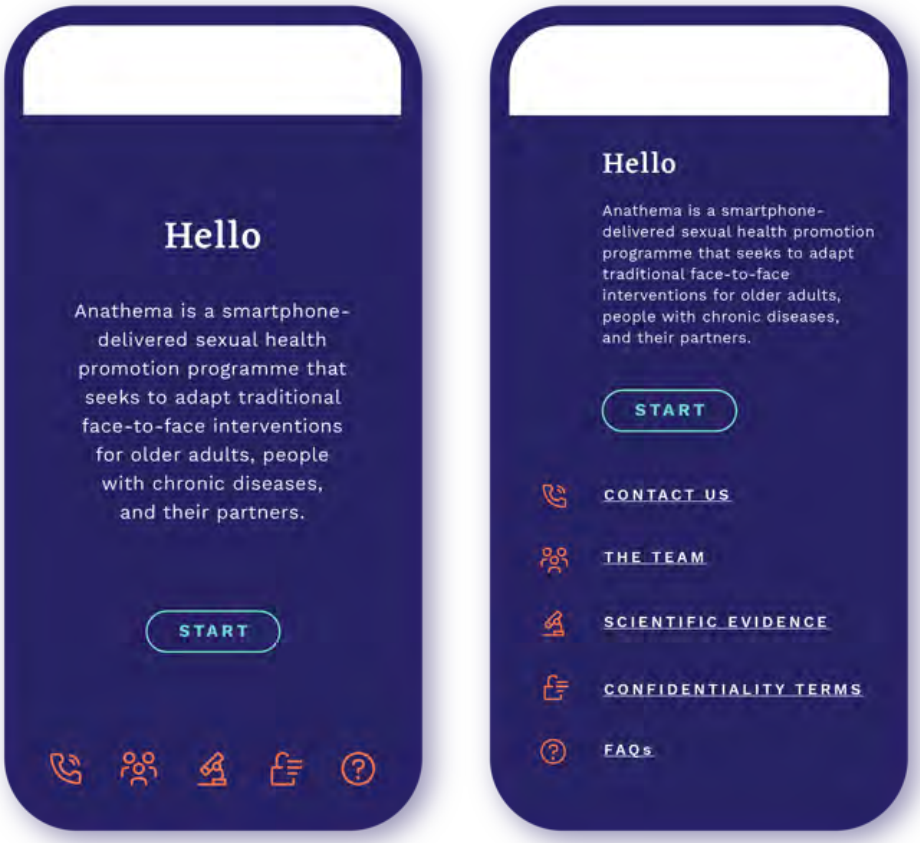

Figure 4. Two images used for the trustworthiness exploration.

The same images were shown in an online questionnaire (**Activity 5**) launched in the Netherlands, which got 111 respondents. Results from Activity 5 confirmed those in Activity 4. Participants preferred a tone of voice that is Serious, Casual, Respectful and Matter of fact, with a certain openness to wit. This tone combination is consistent with what NN/g (2016) found for health-related websites. To participants, a screen with visible button labels was not more trustworthy than one without. Participants preferred a cleaner screen and requested plainer language. We also learned that participants preferred following the programme in self-guided mode rather than having support or guidance from a sexologist.

Activities 6, 7, and **8** delved into anatomical illustrations. Especially when prominent on the screen, illustrations can be a sensitive matter, thus we wanted to understand how to best design them to be appropriate and non-stigmatising. We also tested whether abstract and metaphorical variations could be used as app illustrations, e.g., in splash screens or screen transitions (Figure 5, Figure 6). From Activity 4, we learned that meanings of metaphorical and abstract images are difficult for users to grasp. For educational purposes, all users prefer figurative images, but there are nuances. The first nuance is cultural, as users in the Netherlands did not want to feel schooled about anatomy, while Portuguese users found it relevant. The second nuance relates to sex: whilst all were generally comfortable with the representation of male genitalia, female genitalia raised several discussions because the woman looks exposed and, for some users, it

invites penetration. This is critical to healthcare professionals, not least because, for some colorectal cancer (CRC) survivors, penetration may no longer be possible. Finally, all users feel uncomfortable with too much context, especially for vulvas, e.g., pubic hair, buttocks, inner thigs. This might be related to how historically vulvas have been represented and which are being challenged today (Strömquist, 2018).

For **Activity 8** participants were CRC survivors, as well as CRC healthcare personnel. We added ostomy bags and stomas (an opening in the abdomen connecting to the intestine) (Figure 7) to the existing illustration. In this activity there was misalliance among participants: whilst CRC survivors were comfortable with the figurative images because they were able to understand them, healthcare professionals suggested that images should be more abstract not to shock or school CRC survivors, and deter them from using the app.

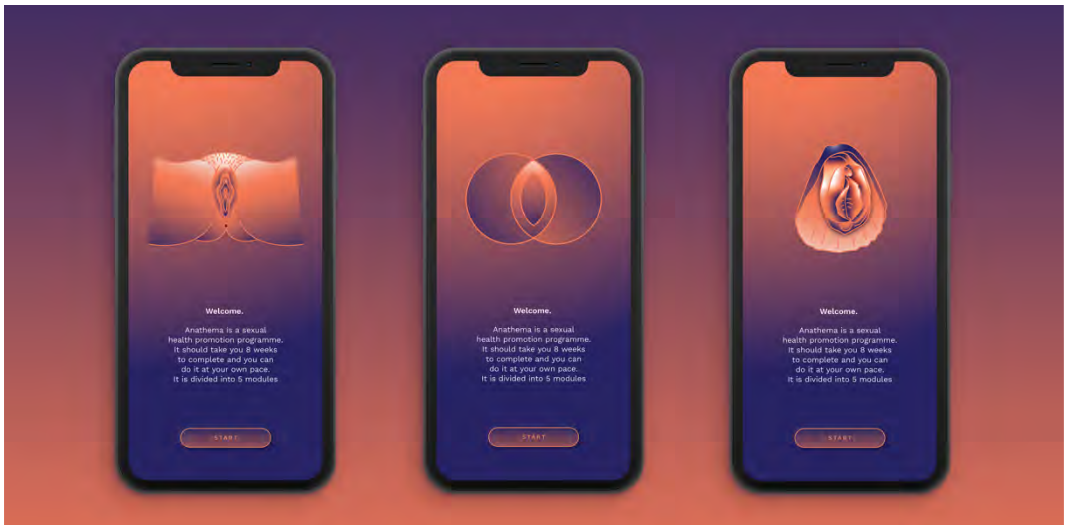

Figure 5. Figurative. abstract and metaphorical female genitalia

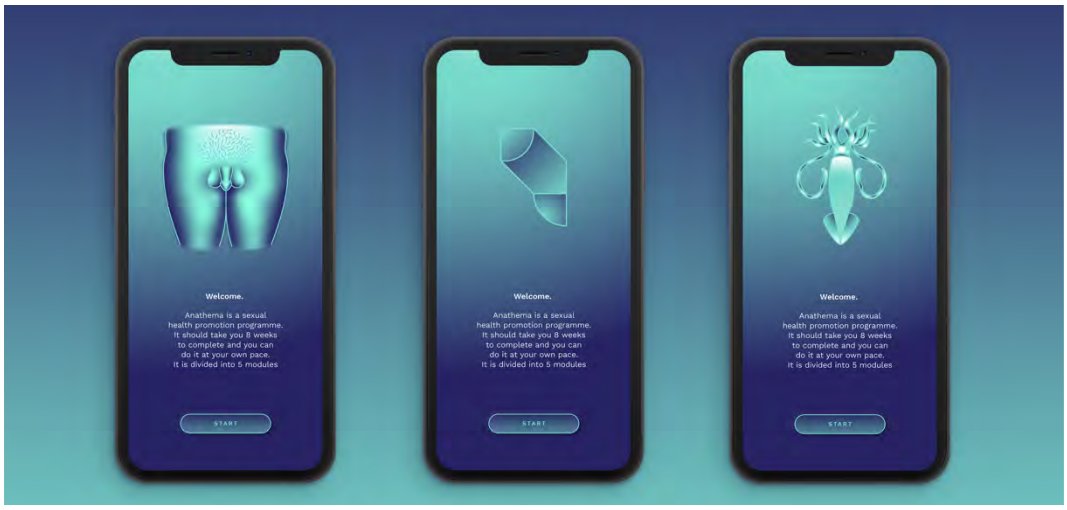

Figure 6. Figurative. abstract and metaphorical male genitalia

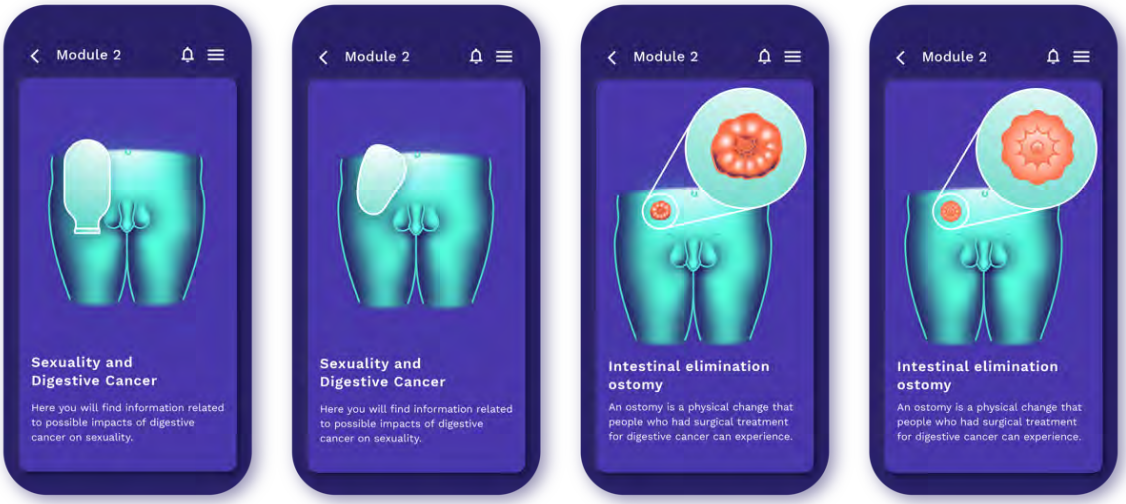

Figure 7. Images of ostomy bags and of stomas

Rules of etiquette – Phase 2

Human sexuality is a highly sensitive topic, especially when coupled with ageing and disability. We learned that perceptions vary between countries, between patients and healthcare professionals, and we also learned that what people find appropriate differs for male and female genitalia illustrations.

We understood that, while the smartphone can be considered an intimate and ubiquitous technology, it can also be a third element in a relationship, drawing the couples' attention away from one another. It can be, in effect, an agent (Latour, 1992).

Considering the exposed above, we can see that the subject of design in this case is the behaviour of this agent in the different situations it finds itself in. This agent can be conspicuous when bringing users' attention to something in the sexual health promotion programme that is worth paying attention to, but it should be discreet enough not to stigmatise users. This agent should, in some situations, show users images that they can easily interpret, but, in other situations, use ambiguous imagery to stimulate users' imagination.

This agent should have a serious, casual, respectful, and matter of fact tone to amplify the fact that this is an honest and evidence-based programme that does not promise what it cannot deliver. But it should also employ humour as a resource to put people at ease when dealing with taboo issues.

This agent may be interacting with people with or without a sexual partner. Some users seeking support from the app may wish to learn everything about human sexuality. Some might be offended at the idea of an app wanting to school them about their own bodies.

Therefore, to design an app that would be inclusive of all these different needs, rather than striving for design guidelines, we explored the concept of *Rules of Etiquette*, the sub-parts of which are described next.

The rules in theory

Behaviour and aesthetics

For couple exercises, the app should have a discreet presence, so that couples focus on one another – one of the main goals of these types of programmes. However, an experience that stimulates the senses may be useful for learning – another main goal of the app. Instead of choosing one end of a spectrum, light (soft) or bold (intense), we adopted a strategy to address both behaviours (Figure 8): when the user is alone, learning about sexual health, the app will have an impactful interaction with bold aesthetics, whose intense presence, when users are exploring and discovering new things, will support them on didactic tasks. However, when the user uses the app with a sexual partner or in a public context, the application adopts quiet and subtle behaviour.

The app's imagery and aesthetics strive to enchant users. Enhancing aesthetical diversity, may foster distinct ways of seeing, allowing users to feel more open about the unexpected through diverse compositions.

Figure 8. Behavioural spectrum given by graphical conspicuousness

Appropriation and flexibility

People may appropriate products in ways designers never anticipated (Akrich, 1998; Dix, 2007) – a phenomenon which is documented in disability and inclusive design studies (Jacobson and Pirinen, 2007). When needs arise, users may appropriate technology at hand, and thus, the more flexible the technology, the easier the appropriation (Dix, 2007). Indeed, flexibility in use is also one of the traditional inclusive design principles (Mace, Hardie and Place, 1991) and, here, it should be flexible to account for gender identify, sexual orientation, among others.

Rather than app personalization, our etiquette favours flexibility, encouraging users to engage and discover what seems unrelated to meaningful content. Personalization of content can force users into their known range of interests, whereas offering an alternative method for content discovery, including branching, will prompt information unforeseen by users (Melo and Carvalhais, 2017). Diverse interpretations and appropriations of the app are expected to contribute to a sense of usefulness, ownership and, hence, increased use (Dix, 2007).

Providing flexibility of choice allows users to choose their relevant path and content (Figure 9). Additionally, enabling users to skip steps rather than defining a prescriptive procedure will allow tailoring personal experience at one's own pace.

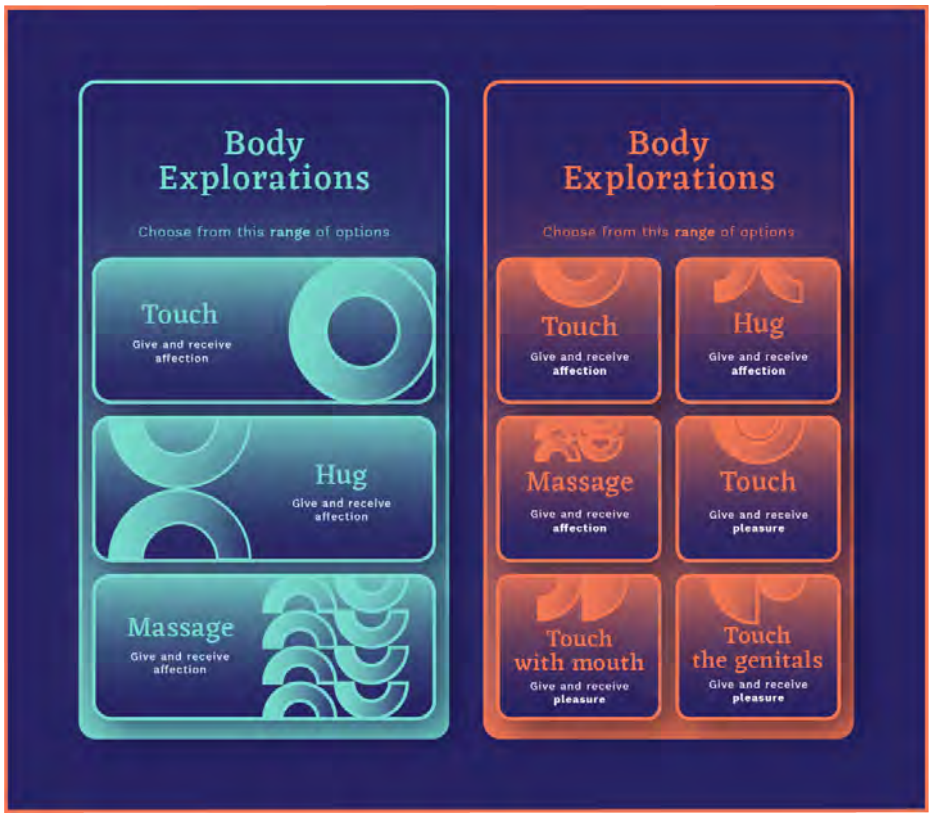

Figure 9. Range of options in body explorations

Serendipity

Appropriation and flexibility at once promote and are augmented by serendipity, i.e. pleasurable accidental discovery. This app as an agent should use serendipity to encourage positive engagement with the app and one's sexuality. Designing for serendipitous encounters will predispose users to engage with the app while sustaining routines for couple interaction, along with communication and self-discovery. The app could perceive nearby proximity to recommend or unlock exercises requiring the couple's involvement. To Melo and Carvalhais (2017), this proximity awareness pattern is indeed a serendipity pattern.

Through Activity 4, we understood that users do not appreciate the presence of a third voice in the application dialogue. To mitigate this feeling, the app could deliver information via discreet hints to guide users. As an example, hints could appear as notifications when the phone is locked, but without revealing information in full to protect users' privacy (Figure 10). Only when the phone is unlocked, are users able to see the full content designed to guide users to accomplish exercises or engage with new ones.

Figure 10. Notifications do not disclose sensitive information

Pre-testing the rules in practice

We did a two-week experiment with two adults (both had sexual partners) to simulate the experience of receiving hints for couple interaction. At unknown times of the week, each participant received a card (Figure 11). For each card, the participant could choose to dismiss, shuffle to get another card or see more, in which case the back of the card would be shown. To explore the role of aesthetics, one participant received all hints with the same graphics, while the other received always different graphics with varying degrees of complexity in terms of colour palette, number of elements, or prominence on the screen. We did post-experiment interviews with participants about their experience.

From this brief experiment, we learned that participants could identify the best times of the day/week to receive hints, that surprise of receiving a hint and variety in aesthetics enhanced user experience, and that abstract images let users imagine meanings for the graphics. It seems that more suggestive than prescriptive content is preferred, because it helps participants appropriate the hints. The tone of voice of such a proximal agent was something participants positively alluded to, especially the fact that it did not seem to speak like a regular app.

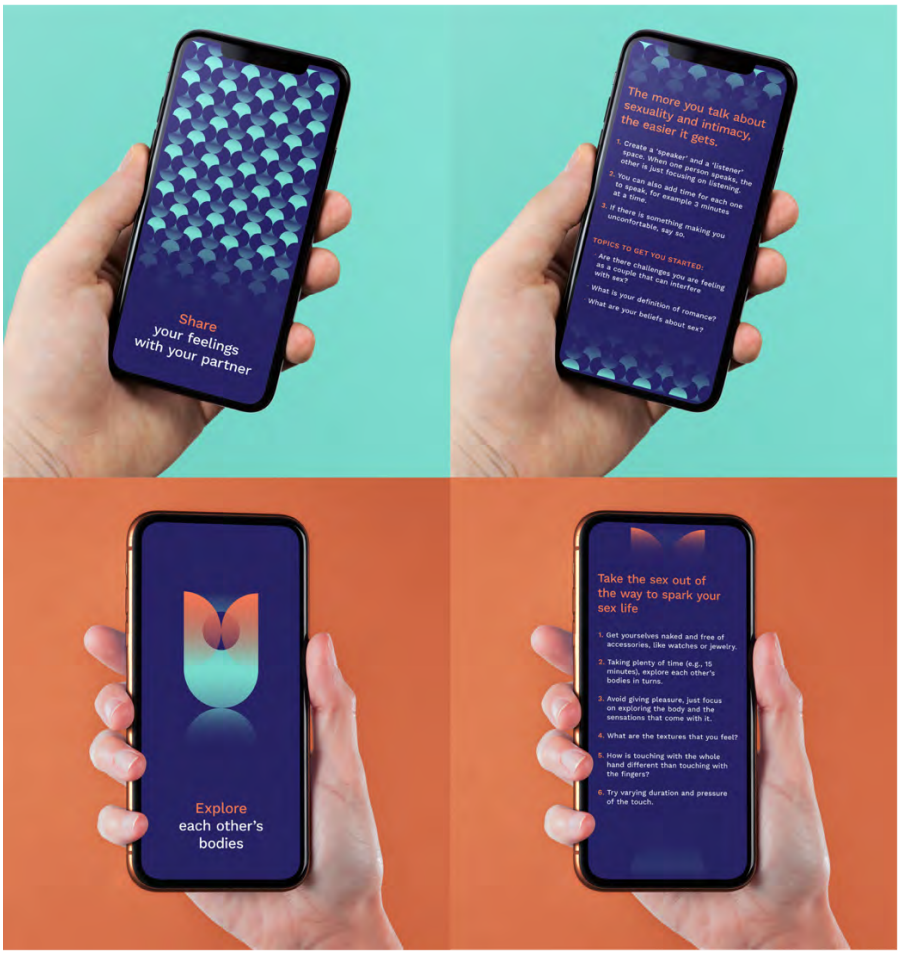

Figure 11. Examples of two hint cards (front and back)

Conclusion

We reached the suggestion of *Rules of Etiquette* after conceptualising the app as an agent. Although we have not yet tested the concept at scale, which is a significant limitation, we consider this can be a concept to explore by other applications especially in interaction design, where inclusion level can be determined by behavioural appropriateness of the digital agent.

Rules of Etiquette may be more ambiguous and, therefore, more challenging to implement, and certainly need to be complemented with traditional design guidelines. However, growing communities designing for intangible interactions and for sensitive topics may find that considering technology as an agent and focusing on its behaviour may prove to be a valuable resource towards inclusion, since, to users, this behaviour will determine what is or is not appropriate.

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Museums and Neurodiversity

Designing safe, accessible and interactive experiences for neurodiverse children

Adity GUDI*
Indian Music Experience Museum

Shivani SHAH
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Sonal RAJA
ReReeti Foundation

Sowmya SANAK
Svarakshema Foundation

Cultural institutions like museums are often sensorially unsafe and overwhelming for children with neurodiverse needs (CwNn). This can make access difficult, excluding them from fully experiencing culture. This paper details the Indian Music Experience Museum's (IME is India's first interactive and experiential music museum) pilot project aiming to create a safe, inclusive tour experience and engagement through music therapy workshops with home-based musical toolkits for CwNn.

Using a participatory action methodological approach, 55 caregivers of CwNn were surveyed, 10 parents and 6 disability advocacy professionals were interviewed. Seventy-five percent of the survey participants have Autism Spectrum Disorder (ASD), 18% Intellectual Disability (ID) and 16.6% a dual diagnosis respectively. Online surveys, focus group discussions, interviews, and site visits, were conducted to gather qualitative and quantitative data. Further, toolkits were designed and customised instruments were developed.

Three focus areas of this initiative were: modifications to infrastructure to create a barrier-free environment, immersive tour experiences, and music therapy workshops. Both the tour experience and the music therapy workshop received positive feedback. An evaluation of the efficacy of musical toolkits indicated improvements in the parameters of cognition, social skills, and behaviour. The initiative explores opportunities to integrate and engage CwNn in public places.

***Keywords**: museum; neurodiversity; accessibility, music therapy*

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Context

Museums are centres of information and exhibits on culture and history. Specifically, music museums are resplendent with auditory and visual information on different genres of music, in this case, the Indian Music Experience Museum (IME – the first of its kind interactive and experiential music museum in Bengaluru, India). This exposure could be sensorially overstimulating for Children with Neurodiverse needs (CwNn), limiting them from fully experiencing music in various forms. This paper details IME's initiative to create safe, inclusive and interactive experiences for CwNn. The initiative opens up this unique 'public space' for CwNn, in a country where there is a dearth of access to such spaces and limited understanding and awareness of both neurodiversity and accessibility. [Provision for disability certification to individuals with Autism Spectrum Disorder (ASD) has been introduced only in The Rights of Persons with Disabilities Act, 2016.]

Museums can be agents of cross-cultural understanding, fostering social inclusion and promoting diversity (Sandell, 2003). Opening up such public spaces for all is one of the many ways to ensure inclusion and leverage diversity. Inclusion and integration of CwNn into public spaces begins with understanding neurodiversity and identifying the scope of support. "A Parent's Perspective" stresses lack of preparedness and exposure to sensory stimulating environments (Bee, 2019), especially sudden unexpected sound triggers (Gaines and Sancibrian, 2014), as one prominent reason for CwNn being excluded from visiting public places (Bee, 2019). This strongly suggests the relevance of adding music, spatial re-organization and other relevant materials to meet design recommendations (Gaines and Sancibrian, 2014).

The museum applied a participatory and therapeutic approach to make it neurodiverse-friendly by:

I. Making the museum space barrier-free,

II. Building an understanding of neurodiversity and creating customised tours for this population, and

III. Curating interactive music-based workshops and handing them take-home instrument kits, which could potentially have a therapeutic impact on the long-term and offer sustained engagement with the museum (McPherson *et al.*, 2019).

Aims and objectives

- **Inclusion:** Making the museum a space that provides equal access, experiences, opportunities and resources to all.
- **Accessibility**: Removing physical and psychosocial barriers in the museum to create easy access
- **Safety**: Making the museum a welcoming and safe space for CwNn and their caregivers.
- **Learning**: Providing experiential and exploratory learning options, that allow CwNn to comprehend, process, reflect and retain the experience beyond their time at the museum.
- **Engagement and opportunity**: Creating meaningful engagements that are interactive and enjoyable; leaving CwNn with a happy memory of the space and a desire to revisit the museum.

Ethical considerations

Careful consideration to protect the rights of the children and parents participating in the research was taken. Any legal decisions or choices for an Indian citizen below 18 years of age (considered as a minor / child) are taken by immediate family, i.e. parents / guardians / caregivers or the applicable government authority, as the case may be. Based on this premise, consent for participation in this initiative was obtained from caregivers of CwNn, in cases where children could not make informed decisions for themselves.

- **Sensitivity and transparency**: The research intent and the process was explained in detail to the participants to ensure protection against any inadvertent distress. Survey questionnaires were translated into the local language to enable informed participation.
- **Consent**: Signed consent was obtained from the caregivers prior to the survey, tour and workshop to gather and analyse the data, photograph and video record the experience to document, share on media, use in research and publish, sensitively.
- **Confidentiality and privacy**: Any identifying information pertaining to the child or institution was used for research purposes only.
- **Exposure to music**: Music-based interventions have no known side effects. (Geretsegger *et al.*, 2016) Additionally, the instruments provided in the music therapy kit were checked for child-safety standards in terms of the material and design.

Methodology

Participatory research method was adopted in this initiative due to limited models and data in this area, in India. This allowed the research participants to be actively involved throughout the project and the facilitators to understand the participants' view of the problem to arrive at recommendations collaboratively. The three different focus areas under this initiative were:

I. Museum infrastructure: creating a barrier-free environment
II. Designing an immersive musical tour
III. Engagement through music therapy workshops

Inputs from relevant specialists, who were invited to experience the museum, were incorporated into the execution.

Research Phase

I. Creating a barrier-free environment

Preparedness to become an inclusive museum

Access (onsite and online) and safety audit of the museum were done to identify the challenges and recommend design modifications to meet the accessibility requirements.

Reaching out to CwNn

Multiple organisations were reached out to discuss the intent and plan of this initiative, encouraging participation of CwNn. A pre-visit survey was sent out to

prepare the museum staff for all the necessary and special requirements of each child. Fifty children of age group between 6 -18 years with diagnosed ASD and/or ID, participated in the tour with their parents/caregivers.

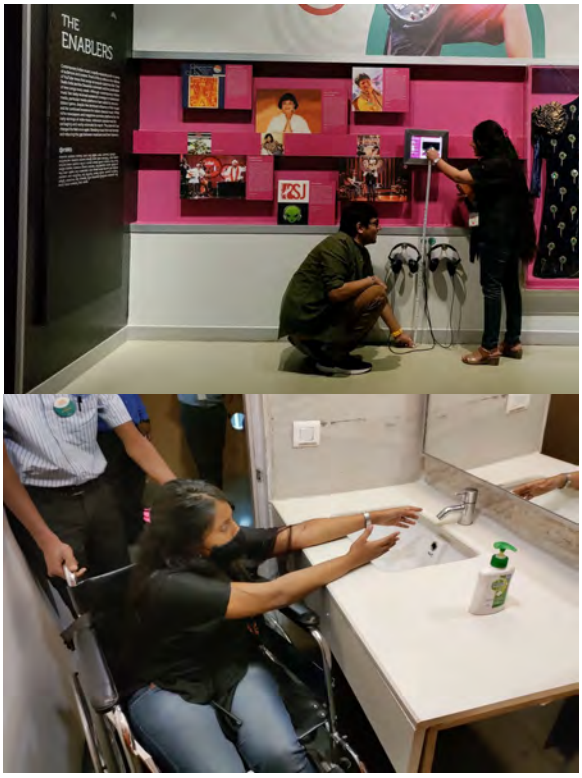


Figure 1. a, b - Accessibility Audit

II. Experience - Immersive tour development

Method

The study was undertaken over 4 stages:

- Secondary research: literature review, case studies and site visits
- Data collection:
  - Quantitative data collection (bilingual pictorial online surveys)
  - Qualitative data collection (focus group discussions and interviews)
- Findings and Analysis

Sample: Fifty-five CwNn were surveyed aged between 6-18 years with a diagnosis of ASD and/or ID. Sample selection was through open invitation to participate. Participants were from special and mainstream schools, and partner organisations. All of them had access to the necessary technology, enabling them to fill out online designed questionnaires for quantitative data collection. Ten parents with their children and 6 sector experts were interviewed for an in-depth understanding of qualitative aspects about the target group.

The purpose of the survey was to understand:

- Individual needs based on the diagnosis
- Entertainment and relaxation activities
- Experience & relationship of CwNn with music

- Challenges and limitations faced by CwNn in a public place

Findings from the survey

Sample demography

From the sample, the majority (75%) of participants had ASD, 18% had ID and 16.6% had a dual diagnosis. Many children also have comorbidities.

Understanding the CwNn

Most of the children (80%) did not need assistance in self-care, 50% of them needed individual assistance while navigating a space. Approximately half (52%) of the respondents shared no ability to recognize signages, with only 16.4% able to read and recognise them. For communications, 45% of the participants used both verbal and non-verbal methods like signages and gestures, 30% communicated only verbally and 25% resorted to non-verbal methods of communication.

Information regarding museum tour design

The majority of children (55.6%) surveyed had not been to any museums before. Those who have visited reported liking experiences that allowed movement, exploration, hands-on activities and catered to their sensory preferences. Some (15%) children disliked museums because they felt bored, disliked exhibits, sensory aspects (e.g., dark spaces, crowds, sounds) and long waiting times.

Most parents report that during behaviour dysfunctions, having a calming zone, or exposure to interesting audio/visual activities like listening to music, screen time, etc. helps their children. The need for transition time or a preparation activity was reported as essential during the tour by 71% of the parents. Most children need structure or clear cues for an activity: of which 54% prefer visual cues and 16% prefer verbal cues. 56% of children prefer being in small groups of 3-4, and 27% prefer individual tours.

Information regarding visit preferences

Majority (58.5%) expressed a need to have details on tour, facilities provided, rest and transition times, prior to the visit. Only a few (11.3%) reported being able to do a 2-3 hour visit without a break, rest needed a break after every 30-60 mins. The majority of parents report that their children are comfortable around strangers only when accompanied by caregivers or familiar adults.

Preferences for music

Majority (85.5%) of children enjoy music. The most liked elements were the tunes and rhythm. The most preferred music is fast and popular following film music.

III. Engagement - Music therapy workshop

Music is an effective learning and developmental aid for children with ASD and ID (Peery, Peery and Draper, 1987). Importantly, music provides an access to the psychology of children with ASD and ID (Zangwill, 2013). Through the application of music as therapy, one can expect tangible improvements in areas of social and communication skills, while their enjoyment of music in itself acts as a motivating factor for participation (Ghasemtabar *et al.*, 2015). Involving both passive and active components of music therapy is critical to offering a holistic outcome for CwNn (McPherson *et al.*, 2019). Passive music therapy involves listening to carefully selected music to help regulate sleep patterns, addressing mood variations, sitting

span improvement and self-management. Active music therapy refers to prescribed personalised activities using musical instruments that help to enhance cognitive and social abilities, improve communication – both verbal and gestural, develop patience by turn-taking, offer a leisure skill and even channelise or divert expressions of anger or frustration. After relevant research, instruments suitable to facilitate musical experiences and therapeutic results were identified and customised to suit the convenience of CwNn while ensuring safety in material and design.

Implementation phase

I. Creating a barrier-free environment

The recommendations from the audit and research were taken forward in two phases - immediate & long-term implementation.

I.A. Immediate implementation

Facility modifications: The following measures were incorporated immediately to make the museum space neurodiverse-friendly.

- **Safety measures:** A number of modifications were done to ensure the safety of CwNn, the major ones being the addition of railings and emergency intercoms to the elevators, speed regulation of the elevators, and anti-skid and reflector strips and beading on the staircases and in the cafe area.
- **Change in the museum timings:** 'Early museum hours' were introduced as an additional choice for CwNn, in case some participants preferred it over public timings.
- **Calming and sensory zone:** Two galleries (that qualified for least stimulating spaces) inside the museum were chosen and modified into a calming zone. Additionally, a classroom was converted to become a temporary sensory room with various sensory elements as recommended by the research findings.

Figure 2. Calming Zone / Sensory Room

Development of toolkit: A communication toolkit that used the Picture Exchange Communication System (PECS)[1] was developed for the tour. It comprised strategies for signalling, gathering, dispersion, transition and activity time. Additionally, cue cards were provided to both the volunteers and children to communicate assistance and emergency needs.

Website: An 'accessibility' tab was introduced on the museum website, providing information on planning the visit, tour schedule and an access guide.

Volunteer training and staff sensitization: Two days of intensive in-person training was given to volunteers (systematically selected) and select museum staff (administrative, facility, security & housekeeping staff). This training included didactic sessions, group work, manuals, handouts, and materials that would be useful during the tours. The groups also worked on various hypothetical scenarios to sensitise and experience challenges that may arise while working with CwNn.

Figure 3. Volunteer Training

I.B. Long-term implementation

- Accessibility requirements like railings, ramps, signages, pictograms, alternative language descriptions (eg. Braille), floor maps
- Permanent sensory room
- Nursing stations

II. Experience -Immersive tour development

II.A. Design parameters

Keeping in line with survey findings and background research, the following six parameters were devised for designing the immersive experience:

[1] Pyramid Educational Consultants. (2014). PECS to SGD: Guidelines and Recommendations for a Successful Transition.Available at: https://www.pecs-unitedkingdom.com/download/PECStoSGD-GuidelinesRecommendations-USA.pdf

1. **Preparedness**: Prior information creates familiarity, builds realistic expectations and a sense of safety.
2. **Relatability:** Using existing knowledge to connect to new experiences
3. **Environmental predictability**: Providing necessary sensory cues to navigate independently
4. **Structure:** Structure and sequence to any engagement helps in mental grouping and provides clarity.
5. **Transitions**: Facilitating easy change and giving enough time to adjust to it.
6. **Sensory customizable environments**: Providing support for varying sensory and emotional needs.

II.B. Tour development

The tour was designed to encourage maximum engagement, keeping in mind the limited time, energy and possible challenges of the target population. The customised tour also included planned-activities. The following were important points of consideration:

- the *access routes*, which would entail the shortest and *least stimulating path* to reach selected exhibits
- the *duration* of stops at each exhibit for exploration and activity
- *the ease* of doing the activities in the museum space, without additional resources or any other background knowledge
- *transitions and breaks* to prevent overload and fatigue
- *hands-on experiences*

III. Engagement - Music therapy workshop

Ten music therapy workshops were conducted reaching out to 100 CwNn. These workshops incorporated aspects of:

- **Passive music therapy**: A playlist, grouped into 4 sets – recommended daily listening, positive reinforcement, meditative relaxing music and immediate diversion music during emotional episodes, was given in a pendrive to the caregivers as a part of the kit.
- **Active music therapy**: Children were taught musical activities, designed to be performed on the chosen five instruments- xylophone for pattern learning, didgeridoo for speech enhancement and breath regulation, cymbals for participative playing and rhythmic cueing, Khanjira (frame drum) for fine motor skills and cognitive enhancement and Clay-bird whistle for self-engagement.

The caregivers were provided with a therapy kit bag containing five instruments, the pen drive and an instruction manual to guide them through the suggested activities. The therapists ensured follow-up of workshop activities and listening as per recommendations.

Figure 4 a.Music Therapy Tool Kit b. Child playing Cymbals

Findings and outcomes

To analyse the impact of this initiative, qualitative and quantitative feedback was taken from the parents/caregivers for both the tour and workshop and additionally from the volunteers, who conducted the tour.

A fun activity was designed especially for children to understand how they felt after the tour (excited, curious, tired, happy, overwhelmed, etc.)

An evaluation of kit efficiency was done through a Google Form, to know utilisation and therapeutic impact, after one month of the workshop.

Impact measurement - Immersive tour

Out of the 50 participants who did the tour, only 33 responded to the feedback forms. The following are the key findings:

- A majority of parents / caregivers gave positive feedback on the tour.
- The most liked element was volunteer sensitivity and conduct, followed by the choice of exhibits, and customised hand-on activities.
- The outdoor hands-on musical installations and the indoor digital interactives were enjoyed most.
- The caregivers appreciated the availability of sensory and calming zones.
- Request for future engagements, including frequent visits, interactive workshops, music courses, and exposure to new galleries.

Figure 5. a,b Children enjoying outdoor and indoor musical installations

Impact measurement - Music therapy workshop

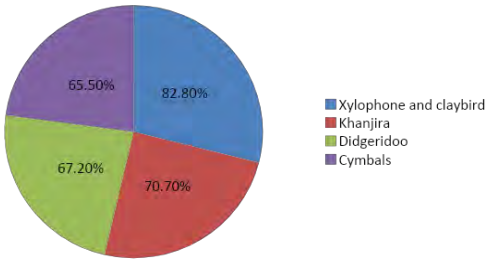
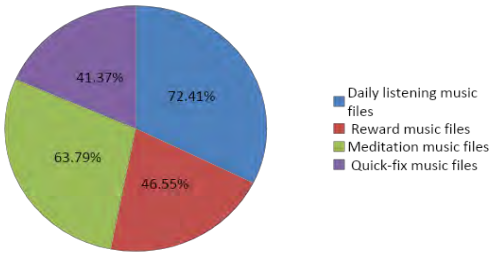
Out of 100 participants of the workshop, the following are the outcomes representing the feedback from 62 participants.

- **Workshop experience**: All the participants unanimously expressed their complete satisfaction and gave a 5-star rating to the demonstration of the Music Therapy Kit with the instruments - their quality and functionality.

Figure 6. Music Therapy Workshop: Child learning to play the Didgeridoo

- **Utilisation data of kit:** The compliance of the caregivers to the suggested set of activities was recorded at 93.54% after one month of kit usage. Nearly 60% of the participants reported utilising both the active (instruments) as well as the passive components (playlists) regularly.
- **Therapeutic goal achievement:** Participants were asked to select up to three therapeutic goals (from communication, behaviour modification, speech, social skills, self-management, fine and gross motor skills, and others) for their CwNn during the workshop and an evaluation of progress in these goals was conducted one month after the workshop through Google forms. Through the use of the music therapy kit, 44.82 % of participants saw fair improvement in all three chosen therapeutic goals, and 58.62% of participants saw fair improvement in at least one therapeutic goal. Based on the frequency of utilisation of the kit, 80% of regular users found fair improvement in at least one therapeutic goal, while less frequent users (31% of participants) have seen certain improvement in at least one therapeutic goal.

Table 1. Therapeutic Goal Achievement based on kit components

Therapeutic Effect of Active Music therapy components (Instruments)	
Therapeutic Effect of Passive Music therapy components (Playlist)	

- **Stress relief for caregivers**: The benefits of the therapy kit were not restricted only to the children as 72.41% of caregivers reported a significant reduction in their stress levels with the use of the kit.

Discussion

The major learning from this initiative is the need to aggregate partnerships that bring in expertise in museums, music, design & architecture, inclusion & neurodiversity, and funding. This implies that a continuous flow of resources is critical to sustain and expand the engagement with other target groups. Additionally, understanding and meeting the demands of the ‘end-users’ is imperative. It is important to explore how this initiative can holistically cater to both

the CwNn as well as their caregivers. In our understanding, exclusiveness, by providing choices and customised experiences for the neurodiverse, leads to inclusion.

Limitations and challenges

- **Lower than expected participation**: Due to the higher susceptibility of CwNn to infections and illness, the caregivers expressed hesitation to visit public places, such as the museum, especially owing to the pandemic.
- **Facility modification**: Implementing infrastructural recommendations were challenging as the main design and civil work of the building could not be changed.
- **Funds**: This museum being a non-profit organisation, had limited availability of funds. Hence, some of the audit recommendations for immediate implementation were deferred.

Future recommendations

Some suggestions that were derived from discussions post the implementation and would go a long way in reaching the benefits of inclusion are:

- Spreading awareness about Neurodiversity
- Focus the impact measurement of such initiatives towards enjoyment & therapeutic outcomes instead of educational outcomes
- Expansion of the initiative's scope to accommodate other conditions requiring customised experiences
- Inclusion initiatives in public places can begin with bringing in enablers such as sign language interpreters, Braille, signages, etc.
- Design similar initiatives for adults with neurodiverse needs.
- Public places could curate events that are neurodiverse-friendly like film screening and drum jamming & opportunities to showcase their talents regularly.
- Introducing a dedicated space to build sensitivity and celebrate diversity.

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Feeling Seen and Heard

Exploring the lived experiences of art students with dyspraxia through experiential workshop participation. An evaluation of the advantages of flexible modes of engagement

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This paper discusses the benefits of workshop participation as inclusive research practice. The workshop reviewed was designed to explore the lived experiences of art students with dyspraxia in a collaborative and mutually beneficial manner; aiming to create a space for students to discuss the different aspects of dyspraxia; including etymology, existing research and impact on higher art education. It provided an opportunity for students to ask questions and access information as well as explore new practices, share experiences, and collectively strategise.

The workshop contained information sessions; practical workshops, forum debates, guest speakers, reflexive practice and discussions, providing the group with a reflective space to engage in stimulating debate. Feedback revealed that with peer support, the workshop delivered an opportunity to process concerns surrounding diagnosis and experiences of dyspraxia.

Feedback and discussion demonstrated the benefits of guided group workshop, together with continuous dialogue, as a framework to provide support in both the creation and dissemination of support strategies. The inherently empathetic group dynamic enabled students to confidently and critically respond to discourses surrounding neurodivergence. Indeed, numerous students remarked feeling empowered through the collective voice, where they would previously have remained reticent, feeling unable to contribute and their opinions gone unheard.

Keywords: *neurodiversity; dyspraxia; neurodivergent art students; neurodivergence in higher education*

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Synopsis of research

The intention of this workshop was to investigate, without expectation, the potential of workshop participation for exploring the lived experiences of art students with dyspraxia. This paper is an account of that workshop, which took place in 2017. Due to word count considerations this paper will limit details to sessions where the author led activities. It involved MA art students across the RCA with dyspraxia, while remaining inclusive for students without dyspraxia interested in neurodiversity. The workshop took place over five days, consisting of a series of activities and sessions primarily led by Emily Öhlund. Selected sessions ran in unison with or independently by Antje Illner and Alison Mercer.

Because the workshop was inclusive for students with or without dyspraxia, this resulted in students attending who suspected they were dyspraxic but had not sought diagnosis. It became clear during discussions, that one of the principal reasons for this decision was a fundamental disagreement with the deficit model and labeling paradigm. Nevertheless, the students were struggling with the same challenges as those with a diagnosis and were attracted to the workshop as a means of support.

Together, the group explored and interrogated narratives surrounding neurodivergence. Through collaborative participatory workshop activities and discussion, the students considered and recontextualised shared experiences of being dyspraxic students. The act of sharing enabled the group to create an open forum for constructive dialogue and exploratory practice, facilitating discussion around common issues and encouraging the development of strategies to benefit their creative practice. Their active participation in the research process reinforced their agency in designing their own support systems and strengthening confidence in self-sufficiency.

Figure 1. Workshop activity

Introduction

Research suggests students with dyspraxia commonly experience anxiety, stress and self-confidence concerns, (Skinner & Piek, 2001; Pearsall-Jones, J et al., 2011; Waszczuk et al., 2016; Yao-Chuen, 2017; Blank, 2019) especially in higher education (Öhlund, 2017, 2018; Riddell et al., 2005, Pearsall-Jones et al., 2011, Williams et al., 2015; Penketh, 2007). The diagnosis of dyspraxia can be confusing (Gibbs et al., 2007) and students do not always seek diagnosis or the support that they are entitled to (Riddell et al., 2005) – support that they need to cope with the demands of their studies (Penketh, 2007; Penketh, 2011; Öhlund, 2018; Rankin, 2020). Subsequently they may go through their degree programmes without implementing support strategies or making tutors and peers aware.

Existing research investigating dyspraxic experience is typically interview-based, predominantly relying on the individual's ability to timely answer questions, giving paramount significance to spoken language as a means of communication (Williams et al., 2015). Dyspraxic individuals typically struggle with auditory processing and structuring thoughts in order to verbally communicate them (Kirby, 2011; Carey, 2014; Williams, 2015; Sartori et al., 2020) therefore this approach has limitations and used alone may fail to provide a true reflection of the individual and their experiences (Roy, 2013). Greater consideration should be given to the nature of dyspraxia as a processing difficulty when designing research methods, recognising that processing time varies and providing adaptable modes of engagement in order to meet the needs of the interviewee.

Recent studies have explored dyspraxia within art higher education incorporating other communication methods, such as engaging with materials and drawing (Öhlund, 2017; Rankin, 2017; Riley, 2018; Rankin, 2020) in order support participants to recognise and elucidate their processes during interviews. Nevertheless, further scope remains for researchers to provide dyspraxic art students with the opportunity and means to design their own research methods and support tools by involving them as collaborators in the research process. Such participatory frameworks enable dyspraxic students to design their own solutions for the difficulties that they face, examples of which can be found in existing neurodivergent collaborative-design research (Guhu, 2008; Francis, 2009; Gaudion et al., 2015).

Aims and Objectives

The aim in designing the workshop was to create a space early on in the student's Master's degree, to discuss the different aspects of dyspraxia; including etymology, current research, impact on art higher education and the arts. It was an opportunity for students to ask questions and access information as well as explore new practices, share experiences, feel seen and heard and collectively strategise. It was exploratory in nature, with the intention of unpacking aspects of dyspraxia together with dyspraxic students. The principal researcher, Emily Öhlund, also dyspraxic, was an empathetic guide who understood first-hand the struggles being experienced. Öhlund's PhD research (Öhlund, 2017) also explores experiences of dyspraxia in higher art education, which informed the design of the workshop.

The workshop trialed the notion of a physical space for students to address issues regarding their diagnosis with peers and become a part of creating solutions and strategies to support themselves and their fellow students. Over the course of the week, the students established a supportive peer network and subsequent feedback suggested the network remained in place throughout their MA programmes.

Ethics

The RCA ethics committee granted ethics approval and information sheets and consent forms were sent out ahead of time and signed on the day. Students were asked ahead of time if they required any particular set up during the workshop or seating situation. The group were asked again if they felt comfortable in the space on the first day and ongoing adjustments were made including moving blinds; swapping seating, adjusting volume and brightness on films and presentations.

The Adult Dyspraxia Checklist (Kirby, 2008) questionnaire was filled out ahead of time, helping to establish where students struggled most, helping shape the focus of the information sessions and discussions. Material such as films, journal articles and books that informed struggles was provided and discussion would arise out of response to these. At no point were questions put directly to students. Forum sessions, guest speakers, literature or workshop activities resulted in questions from the students, which developed into discussion, during which students chose to share opinions and experiences. The researcher ensured that conversation was constructive, positive and respectful in character. Students were made aware of support available to them if they were affected by anything in the workshop. This was reiterated in writing in the consent form and email correspondence before and after the workshop. It was made clear that they could leave the workshop at any time and withdraw consent without providing a reason.

Methodology

Figure 2 illustrates the three modes of engagement contained within the workshop series; creative practice, information exchange and discussion. Within those key modes were information sessions, open forum debates, guest speakers, readings, practical activities, and opportunities for reflection and discussion. Figure 3 details the workshop activities, demonstrating the range and sequence. 27 students took part; 8 students with a diagnosis of dyspraxia, 9 non-dyspraxic students, and 10 students who suspected that they were dyspraxic and were debating the diagnosis route. The group was given the autonomy to move their work in any direction that they wanted during the week. Opportunity was given for students to suggest workshop themes in advance, with additional opportunities throughout the week to propose directions to move the group. The preliminary responses involved concerns regarding memory and sensory distraction, hence these were central themes.

During Tuesday's activities investigating sensory perception the group expressed a desire to find a 'tool' to manage sensory overload and mindfulness jars were mentioned. Mindfulness jars were written into the schedule for the following day and students brought jars from home to complete the activity. Remaining flexible and adjusting the program to include the group's wishes was integral to the workshop's objective as an inclusive means of exploration and thereby ensuring the positive experience of its participants.

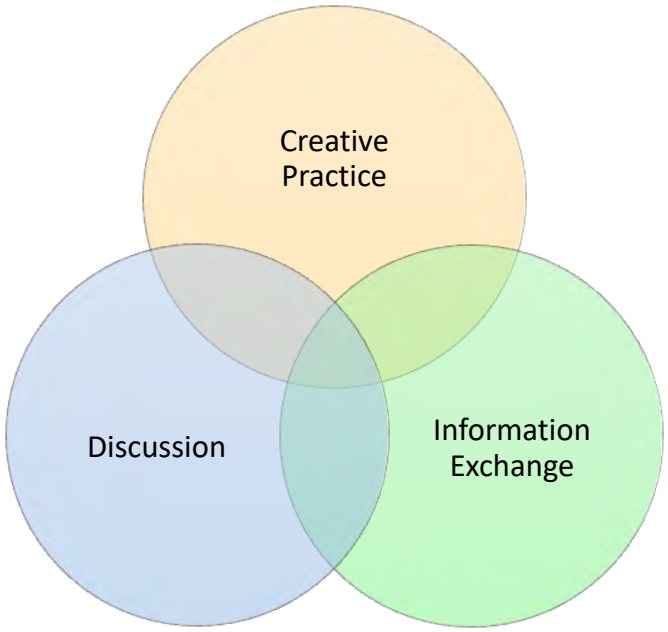


Figure 2. Diagram demonstrating the 3 modes of workshop engagement

The flexible configuration of the workshop gave a framework for the students to engage with in diverse ways. They connected with one another in the common ground of that space and the researchers who led the workshop guided the student's development by being present to answer questions, supporting their development if they struggled to connect with the task, and ensuring that the discussions were constructive, encouraging and positive.

If a situation arose where a student felt frustrated, workshop leaders used the concern as an opportunity to engage in critical thinking; addressing the challenge and unpacking the issue together, working towards deeper understanding and then resolution. An example of this occurred during the reimagining sketchbook activity, when a student felt would not benefit them. The activity leader Alison Mercer deconstructed the activity and the group challenged the idea of thinking as a linear process, reflected in a traditional sketchbook, considering instead the potential benefits of an alternative tool that reflected the dynamic way that neurodivergent people may think. The student felt reassured by the discussion and progressed with the task enthusiastically.

The interchange between the three modes provided the group with a reflexive cycle of activity which informed, nourished and supported one another; information sessions were followed by discussion, which were followed by opportunities to respond through creative practice which were considered through further group discussion and so on.

Workshop Schedule

Creative Practice—Daily Material Interaction: Participants engage with materials throughout the day's activities in whichever way they choose

Monday '*Defining Dyspraxia*'
Led by Emily Öhlund

Information Exchange—Talk:
PhD candidate Emily Öhlund presents her research exploring the lived experience of craftspeople with dyspraxia at the RCA (Öhlund, 2017)

Discussion—Forum:
Exploring notions of neurodivergence, dyspraxia

Break

Information Exchange—Group Reading:
Exploring literature concerning visual memory and synaesthesia

Discussion—Forum:
Considering attitudes surrounding sensory perception and memory.

Break

Discussion—Strategies:
Group discussion around strategies to support challenges. Begin strategy wall to be added to during the course of the week

Tuesday '*About Flow*'
Led by Emily Öhlund

Information Exchange—Talk:
Listening to recorded lecture by Mihaly Csikszentmihalyi on *flow* and creativity

Break

Information Exchange—Talk:
Guest speaker neuroscientist Professor Janet Eyre presents her research (Eyre, 2017; Ushaw, 2017) on how the neurodivergent brain and body can operate in the state of *flow*

Discussion — Q&A:
Open discussion with Professor Janet Eyre on the subject of motor function, *flow* and neurodivergence

Break

Creative Practice — Material Interaction:
Engaging with familiar and unfamiliar materials and processes. Recognising patterns of motor function and the role of *flow* in creative practice

Wednesday 'Memory and Sensory Perception'
Led by Emily Öhlund and Antje Illner

Information Exchange — Talk:
Researcher and jeweller Antje Illner presents her work centering around sensory sensation and haptic knowledge

Break

Creative Practice — Mindfulness Jars:
Creating a mindfulness jar to calm the senses in times of sensory overload

Discussion — Forum:
Sharing sensory experiences and strategies while making mindfulness jars

Break

Creative Practice — Activity:
Visual memory exercise and strategising

Discussion — Strategising:
Sharing memory experiences and strategies

Creative Practice — Outing:
Sketching diverse perspectives along the river side

Thursday 'Material Encounters'
Led by Emily Öhlund and Alison Mercer

Information Exchange — Talk:
Researcher and textile artist Alison Mercer presents her research exploring textile encounters (Mercer, 2016)

Creative Practice — Reimagining Sketchbooks:
Alison Mercer leads an activity challenging the concept of sketchbooks and their potential tools to converse with the subconscious. This task is continued alongside the day's talks

Break

Information Exchange — Talk:
Researcher and textile artist Mah Rana presents her research (Rana, 2020) concerning 'well-making spaces' and textiles making as a means of interaction and connection with her mother who has Alzheimer's and for whom she is a carer

Break

Information Exchange—Talk:
Jeweller Cara George talks about her experience as a dyspraxic maker and her work with neurodivergent children

Discussion — Q&A:
Open discussion with Cara George and Mah Rana about their work and neurodivergent creative practices

Friday 'Reflection'
Led by Antje Illner

Creative Practice – All Day Workshop:
Antje Illner recreates Jivan Astfalk's renowned *Lifelines* (Astfalk, 1999) workshop. An opportunity to reflect on how our experiences and understanding of the world intertwine with our identities as makers

Break

Creative Practice – Workshop exhibition:
Significant fragments from the week are exhibited alongside outcomes of the *Lifelines* workshop

Break

Information Exchange – Pecha Kucha:
Participants present and discuss experiences of the week using their practical outcomes and exhibition as talking points

Figure 3. Workshop schedule.

Practical tasks were used to apply and contextualise themes such as visual memory and sensory overload, grounding notions in their real-life consequence (Pink, 2015). These served as talking points and catalysts for discussion and strategising. The memory task in Figure 4 required the students to rapidly sketch a series of images projected on the wall for 2 minutes. Through the repetition of this activity, various strategies for supporting visual memory emerged. Afterwards the students reviewed the challenge, how they found ways around it and shared their strategies. These included abstraction; imaginative adaptation, synthesis and leaving memory markers to trigger recollection once the projection was gone.

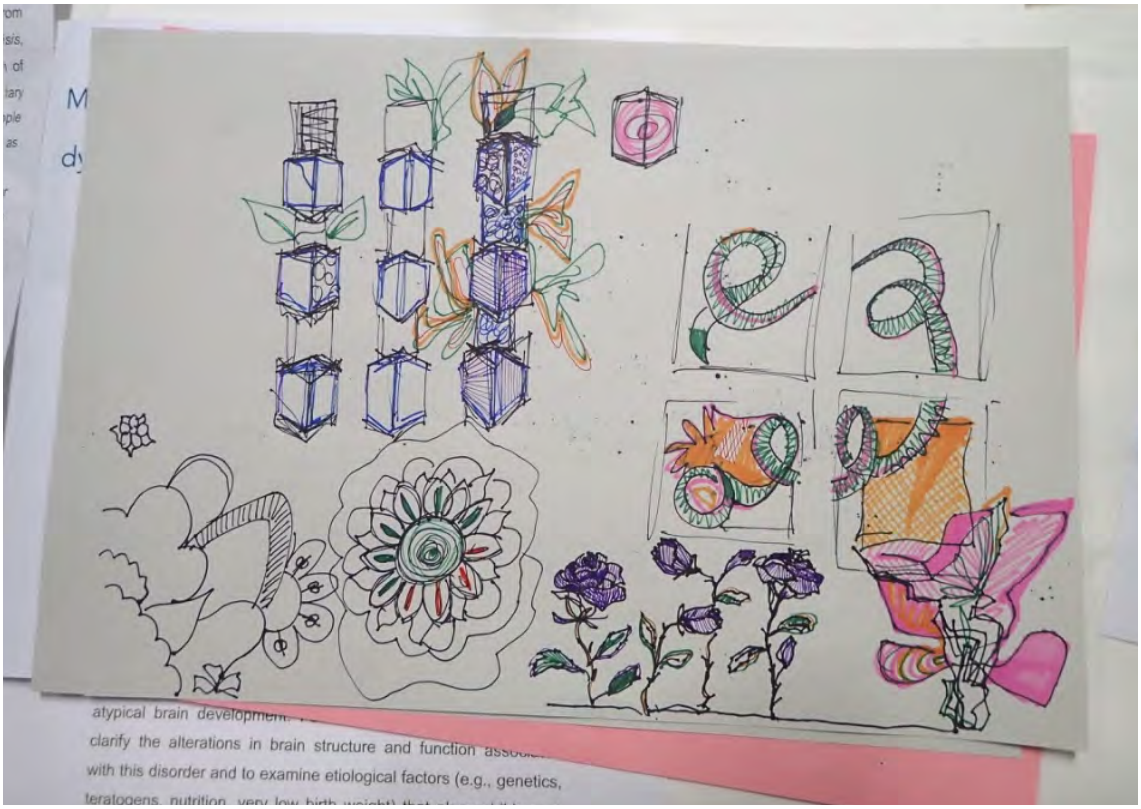


Figure 4. Students' sketches of projected images during visual memory exercise

Another workshop task was to create a mindfulness jar; a popular tool to help manage sensory overload involving a bottle containing gelatinous liquid with small particles or glitter floating inside. When shaken vigorously and placed on a surface, the swirling particles gradually settle down. Watching this process absorbedly helps to regain focus and settle the senses.

Creating these bottles took time and the theme prompted discussion around sensory challenges and other strategies to manage stressful environments or situations. While the end result was a physical tool to support the issue, the process of group making acted as a conduit to discussion.

Figure 5. Student shaking mindfulness jar

Figure 6. Students discussing sensory overload while making mindfulness jars

An objective of the workshop was to give the students continuous access to practical forms of expression so that they had a variety of ways to process their thoughts, express themselves and record experiences and ideas. A wide range of practical materials was available for use at all times. The material outcomes that were subsequently created provide additional insight into the attitudes and interpretations regarding the subjects being discussed and the experiences

connected with them (Biggs & Karlsson, 2011). For example, the student, whose model is seen in Figure 7, described the anxiety of trying to organising her thoughts with humour, laughing while describing it as '*feeling crushed by her giant chaotic brain'*.

Figure 7. Students' sculptural representation of being overwhelmed by disorganised thoughts

Difficulty processing auditory information and organising thoughts makes it problematic to verbally articulate concepts rapidly in discussion situations and can generate anxiety, making the whole process increasingly stressful. The availability of a variety of expressive techniques, including systems of enactment such as model making (Figure 7) (Allen et al., 2014), and tablecloth-notes (Figure 8), created inclusive participatory options which supported the student's ability and confidence to contribute. Objects took on conceptual and metaphorical significance, embodying hard-to-express feelings. These objects were used as prompts during discussions to aid remembering and illustrate notions hard to explain with language alone.

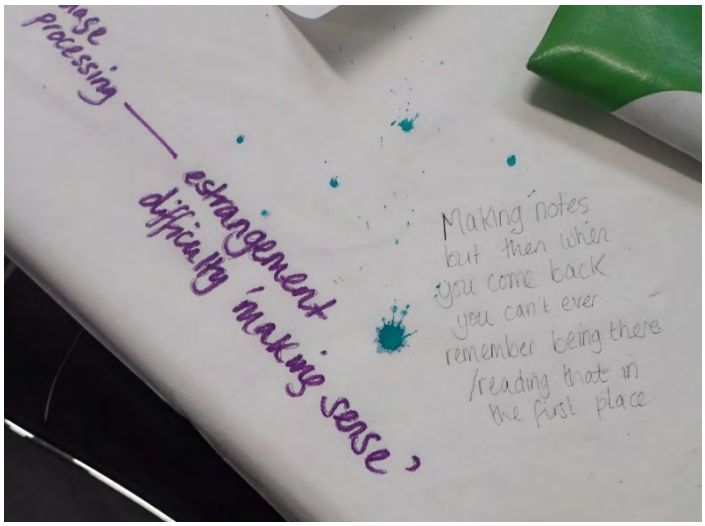
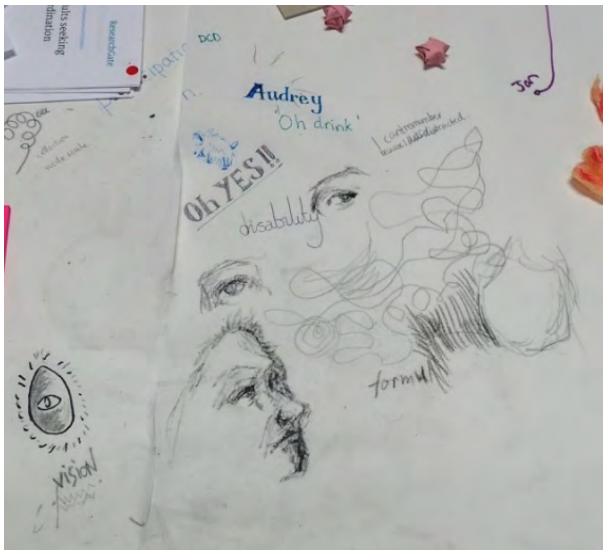


Figure 8. Student's tablecloth-notes during discussion.

The paper tablecloths gave the students a tangible place to rapidly write down their thoughts or note questions so as not to forget them before the opportunity came to ask. Over the five days these notes began to form a 'conceptual blueprint' of the week, consisting of markers illustrating key moments of interest (*Figure 9*). The students valued these 'blueprints', and cut them out to keep at the end of the workshop.

Figure 9. Student's tablecloth notes throughout the week

Because they were visually accessible, they became a point of reference, students continuing to reflect on and add to them, responding to themes through creative practice (Figures 10 and 11).



Figures 10 & 11. Student's notes and sketches during discussion. Student's model exploring themes of neurodivergence, continuing on from notes

Research has linked physical engagement in a task with increased ability to focus (Allen, 2014). Therefore, students were encouraged to engage with material whilst listening to guest speakers and information sessions.

Figure 12. Student's model portraying neurons, created while listening to guest speaker, neuroscientist Janet Eyre.

The students used material interaction to help process what they were listening to during information sessions and group discussions. The act of playing with, enacting or physicalising the information helped to process and retain the new knowledge (Winnicot, 2005; Allen et al., 2014; Carey, 2014).

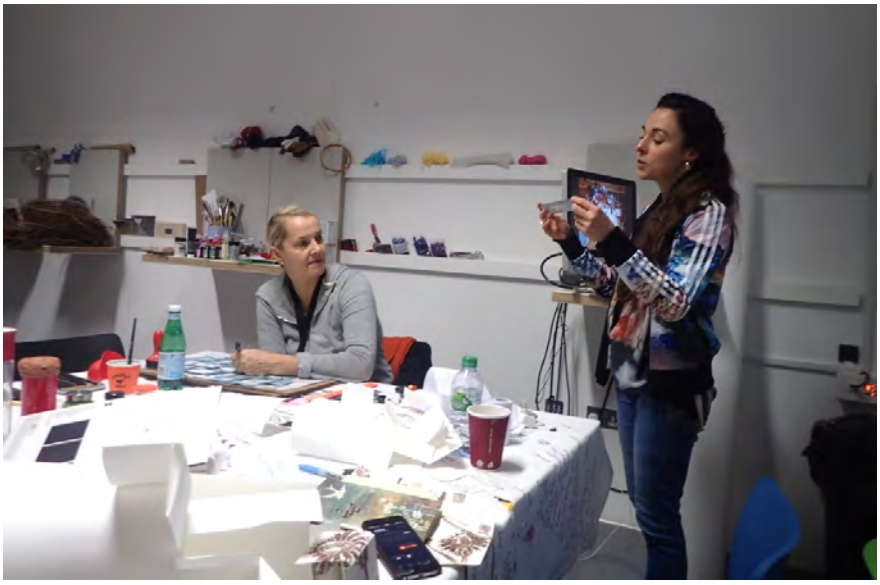


Figure 13. Student painting while listening to guest speaker Cara George discuss her experiences as a dyspraxic jeweller.

Through participatory group research, students critically interrogated theories and attitudes surrounding neurodivergence, comparing these against their own experiences. The intersecting activities informed one another and through collectively reflecting on daily experiences they encouraged each other's development.

Findings and outcomes

Feedback from the participants revealed that they benefited from the support of their peers, whilst the workshop gave them an opportunity to process concerns surrounding diagnosis and their experiences of dyspraxia, accessing information which they would otherwise not known how to locate. They also benefitted from being able to challenge notions that they disagreed with, working through concerns together in order to better understand them was essential to resolving them:

> *Before the workshop I had to live with high levels of guilt and self-hatred that I was so lazy or so stupid I couldn't even get menial tasks done. Someone said, 'If you have dyspraxia, you will quite often find yourself being described by others as lazy.' And that is exactly what was happening to me at the time. I was working so hard — to the point it was detrimental to my health, yet still being described as lazy and unprofessional by my tutor. Now it's great because I understand it's just about strategising ways around it. On reflection, the most important aspect was people sharing their experiences of dyspraxia, and realising you're not alone*

They found sharing and listening to others helped them to positively revisit and recontextualise their negative experiences. The realisation that these *were* shared experiences validated their struggles and gave rise to a sense of relief:

> *It was such a relief to find out that other people experienced similar things to me*

The group experience created a supportive network of students, some of which remained in place throughout their time at the university. A common remark in feedback was finally "*feeling seen and heard"*, an experience which they struggled to achieve elsewhere and after which they felt better prepared to move forward with confidence in their MA studies. This feeling of being listening to and understood was enriched by the realisation of shared experiences.

> *I have rarely learnt so much about myself in such a short space of time or been around that many people with such a high level of empathy on the subject... perhaps due to our shared experiences*

Figure 14. Collective strategies developed during the week

This mutual understanding was particularly apparent in their accounts of their sensory experience within studio environments, which was significantly impactful, yet other students and even tutors were completely unaware. Finding ways to maintain focus was especially important to them. This issue was addressed during the discussions and the group shared and created strategies to help adapt the studio environment:

> *Beginning an important venture threw up a few concerns with regards to certain areas I struggle with. It was great to have a space in which I could reflect on these concerns, look at coping strategies and talk with other people facing similar struggles. Before the workshop my studio space at the college had been left unused, since the workshop I still find elements of working in the space difficult but went straight to work in attending to these difficulties and succeeded in creating work within the studio I could not have done at home. Fellow students have commented on the difference they have noticed*

A significant outcome was the emergence of an attitude of reluctance to pursue the diagnosis route by students who suspected that they are dyspraxic but who were evidently struggling. Objections suggested that one possible implication of the deficit model remaining at the core of diagnosis culture, is a reluctance to partake in diagnosis altogether for fear of pejorative labelling, even at the expense of wellbeing. This dilemma indicates the need for advancement promoting positive attitudes surrounding neurodivergence, including progressing language and attitudes.

Another notable outcome was the diverse range and creativity of self-designed coping strategies presented by the students, once given a range of ways to express themselves. In the visual memory task alone, they displayed compensatory techniques involving the abstraction of visual elements, imaginative elaboration, placing memory markers and the synthesis of visual information.

Significance and implications of study

The evidence from this study suggests participatory workshops involving these three modes of engagement has potential advantages as an inclusive research structure, benefitting both participant and researcher. It also highlights the potential of guided group peer support as a method of early intervention together with forum discussion for the generation and dissemination of support strategies. Dyspraxic students who struggled to articulate themselves and their difficulties, felt able to do so in this situation with the help and support of their peers and a variety of methods on offer. Sharing experiences with their fellow students allowed them to empathise with, truly hear and even advocate for one another when communication faltered. This group dynamic thus enabled the students to critically respond to theories and attitudes surrounding neurodivergence and find empowerment in their collective voice.

Figure 15. Workshop space

Processing information and emotional responses can take longer for a person with dyspraxia (Delgado-Lobete, 2020) and so having an open channel of discussion for a number of days with the option to revisit themes at any point was a fundamental component in ensuring the inclusivity of the workshop. Including a channel of communication, such as emailing the researcher for additional information, helped allay anxieties that they would run out of time to voice their opinions. These options were utilised by the students when thoughts came to them days or weeks after the workshop.

This workshop investigated the benefits of allowing students with dyspraxia to address their experience through a range of intersecting exploratory activities. It illustrates how those provisions affected their ability to engage with the subject in a meaningful and valuable way. The fruitful nature of the workshop was underpinned by the textural nature of the methodology, which provided numerous inclusive options for expression and engagement. The understanding and support that they found in the group gave rise to a renewed sense of self-efficacy and they left the workshop feeling empowered to address struggles, create solutions and implement constructive changes themselves.

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Track 2. Humanising Healthcare

Royal College of Art
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Design for Healing and Recovery from Eating Disorders

A multidimensional design model

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The paper presents a multidimensional, participatory, inclusive, and person-centered model that aims to produce design interventions to support the recovery process from Eating Disorders. The research is situated within the emerging field of Design for Mental Health and grounded in a relational theoretical perspective and methodology. The paper provides a transdisciplinary review of the literature on designing for health and mental health, and it provides a historical overview of mental disorders' models and treatments, highlighting exclusions of factors, narratives, and gaps. The relational framework affords defining Eating Disorders as multidimensional and mediated practices, which allows seeing healing as a process with material and spatial consistencies. The paper introduces the methodology generated to develop the model: an assemblage of methods organized through a multi-phase study that produces an inclusive and materially distributed understanding of EDs and recovery. The first model iteration emerges from the analysis of in-depth semi-structured interviews with participants who successfully recovered from Eating Disorders. The paper describes the model through its actions, elements, layers, and its main aim: to produce pragmatic, evocative, and unconventional design propositions, tackling the relationships Eating Disorders are composed of that allow for a new sense of self to emerge as a new way to negotiate one's life.

Keywords: *design for mental health; eating disorders; relational healing; healing by design; design model*

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Design for health and mental health: context and gaps

This paper is situated in the fields of Design for Behavior Change, Design for Health, and Mental Health. It focuses on crafting a person-centered, participatory, and transdisciplinary design model that generates interventions for recovery from Eating Disorders. This research furthermore wants to contribute to understanding the role of Design in the emerging field of Design for Mental Health. The following summarizes the state of the arts of design research in health and mental health. Design projects and empirical research have been critical components of the health experience (Chamberlain & Craig, 2017: 3); for example, Design has been utilized to improve the usability of healthcare-related environments.

Over the past ten years, there has been a paradigm shift toward exploring the design role in provoking change in healthcare practices (Tsekleves & Cooper, 2017). Design has further been used to explore interventions for specific health issues (e.g., stroke rehabilitation, diabetes) and in defining approaches and theories to design for Behavior Change (Niedderer et al., 2017).

A design field dedicated to mental health is emerging but lacking: design interventions and approaches that could potentially build Design for Mental Health as a discipline exist; however, cohesive theoretical and practical approaches are missing. Shepley and Pasha (2017) differentiate between functionally challenging and cognitively impairing mental disorders. The latter refers to issues such as dementia (Niedderer et al., 2020), while the former refers to issues such as depression or Eating Disorders. Few design interventions exist as well in the sphere of functionally challenging disorders.

Design approached emotions and moods to create an attachment to products or to improve usability (Norman, 2004), recently expanded into Design for wellbeing and mood regulation (Desmet and Pohlmeyer, 2013) and to improve therapeutic communication (Diatta, 2015). Interest is growing around designing for the body and senses (Höök, 2018; Hendren, 2020; Lipps & Lupton, 2018). Finally, design research on Eating Disorders and recovery is missing. In this endeavor, we need to be mindful of the risks of applying design approaches instrumentally to how the medical paradigm approaches mental health, which would disregard the original contribution that Design can offer.

Medical models, social theory and exclusion: contextualizing Eating Disorders

Eating Disorders (EDs) is an umbrella term that refers to the experiences of Anorexia Nervosa, Bulimia Nervosa, Binge Eating, and Eating Disorders Not Otherwise Specified (EDNOS). EDs are considered non-biological and multifactorial. For example, factors contributing to EDs insurgence comprehend individual, familial, socio-cultural, economic, and environmental ones. These factors can emerge differently in different individuals, so generalizing these disorders' etiology becomes cumbersome (Polivy & Herman, 2002). The model that takes care of EDs is the biomedical one, which compares mental disorders to bodily diseases (Bracken et al., 2012). The Diagnostic Statistical Manual for Mental Disorders (APA, 2013; 329), for example, defines EDs through factors focused on the individuals' bodily boundaries, eating practices, emotions, and consequences, excluding factors outside individuals' boundaries.

To understand the reason for this approach, one can look into how the medical practice and the treatment of mental illness historically emerged (Foucault, 2003). The Cartesian dualism between mind and body, and the latter's subordination to the former, rendered bodies available for observation and treatments and allowed the medical practice to emerge. Patients were grouped into hospitals regardless of their issues (physical or mental); therefore, treating mental illness as a physical condition was considered appropriate. In that context, patients' narratives have been silenced. The biomedical model operates through the reduction of factors to observe: this affords higher comparability between types of treatments and allows a better understanding of treatments efficacy (Valentine et al., 2017).

This approach, however, excludes other factors around mental disorders and recovery: e.g., patients' narratives, ways to conceptualize the body, the influences of culture and the socio-material environment, and the concept of recovery. Even though the biomedical model has later evolved into the Biopsychosocial model (George & Engel, 1980), extra-personal factors are still left behind. Eating Disorders can be read through a social lens: according to Bordo (Ruberg, 2020), Wolf (2015), and String (2019), the idea of the thin body, dieting, and fatphobia, are distracting practices, socially fabricated, and grounded in white supremacy, through which reproduce and maintain class, gender, racial oppression.

Lester (2019) considers Eating Disorders as Technologies of the Self (Foucault et al. 1998), defined as socially and culturally produced practices that individuals embody. When referring to EDs, Lester invites us to consider individuals *"carrying the symptom of larger systemic issues"* (84). Treatments for Eating Disorders rarely address the systems that produce them. They focus on allowing the individual to function within them. EDs treatments are developed without including the concept of recovery, which does not have a commonly agreed definition or process (Björk & Ahlstrom 2008). According to the sociologist Garrett (1997), recovery stories usually appear in narrative forms and are excluded from treatment conceptualization because, as narratives, they "*resist measurements*" (263). However, patients' lived experiences have been collected through qualitative lenses: these studies show the importance of integrating narratives into the Design of treatments for EDs (Bardone-Cone et al., 2018). For example, Malson et al. (2011) describes the difficulty for EDs patients to imagine a future healed self. Eating Disorders have been defined as a stubborn condition to treat, but models and treatments have rarely changed. Psychiatrists Fassino & Abbate-Daga (2013:1) define EDs as "*examples of both crisis of psychiatry and its moderate effectiveness, with reductionist approaches playing a role in this regard*." They suggest the need for complex models to look into these disorders.

A relational approach to Eating Disorders: theoretical framework and methodology

To develop a comprehensive model to design for recovery from EDs, we need a theoretical tool that allows us to describe EDs and recovery as multidimensional and distributed phenomena. This research uses a relational perspective, which describes phenomena through their relationships, considering the elements they produce and are composed of, including human and non-human ones. For example, a social media post, a mother, a fridge, and the practice of bullying should all be considered in terms of their relationships and which role they play in one's EDs. This perspective prevents us from investigating phenomena from one singular point of view (individual or structural) (Latour, 2005) and from understanding the body, the self, and healing as relational and woven in socio-material environments.

The self can be seen as an "*unfolding network of relations between biological, psychological, social and environmental structures*" (Heersmink 2020: 7; Wallace 2019). Healing can be considered as the capacity of one's body to create new relationships (Deleuze in Ruberg, 2020). Conradson (2005) describes how healing relationships and experiences are composed of spatial and material consistencies, which allow new dimensions of selfhood to emerge. Recovery approaches by Design should focus on tackling relations that benefit from one's disconnection with oneself, body, and emotions while crafting new relationships to allow a safely embodied sense of self to emerge. The researcher, therefore, developed a methodological assemblage (Law, 2004): various methods, organized in a multiphase study, that allow describing EDs and recovery experiences from different points of view. The methods range from:

1. Collecting lived experiences of EDs survivors, their support networks, and professionals;

2. Investigating the role of the material environment during recovery via ethnographies;

3. Experimenting with imagination to design for healing;

4. Testing the model via ethnographies and probes.

What follows elaborates on the findings of in-depth, semi-structured interviews with participants who have experienced Eating Disorders in the past but identify as recovered for not less than one year (Bachner-Melman et al., 2018). The interview questions addressed people's changing relationships with themselves, their bodies, food, and environments during the healing process.

The method followed ethical guidelines for research in sensitive settings to protect participants' safety and privacy (Liamputtong, 2007). The researcher, for example, chose to work with memories rather than active EDs' experiences and developed a distress protocol to use during interviews to minimize emotional distress. Participants were able to choose pseudonyms when requested. Furthermore, the method followed the concept of saturation: once recurrent themes emerged from interviews, the researcher stopped the recruitment process to minimize harm (Mason, 2010). The researcher collected 14 interviews. Participation was voluntary and compensated with a gift card of participants' choice. The interviews were implemented through Zoom, following guidelines for COVID-19. Interviews have been recorded, transcribed, and analyzed following a thematic analysis approach, which produced the model's first iteration.

Eating Disorders and Recovery: analysis toward a model

EDs have been described as displacement and coping mechanisms (Bruch, 1973): participants' disconnection from their emotional selves and bodies serves the purpose of detaching from EDs' underlying issues and their unsafe or misattuned socio-material environment. EDs allow absenting (Lester, 2019) from memories of trauma, neglect, and abuse experienced during childhood, as mentioned by participants. Contributing factors to EDs start somewhere else, resonate with participants, and are re-directed toward one's body, which is made up as a problem and solution, becoming a project in need of constant maintenance, toward the

pursuit of unreachable thinness. Self-objectification, body dysmorphia, eating, non-eating and exercising afford numbing and detachment, and a precarious sense of being in control of one's environment. Almost all participants mentioned being subjects of body and eating shaming.

If we zoom closer, participants mentioned being part of environments (schools, sports, and familial ones) in which competitiveness, expectations, and perfectionism are at the center of interactions, perceived as transactional goals to self-worth and love. These environments often do not offer spaces to explore one's authenticity and agency, negotiated through withhold and release of control. The material environment enables EDs practices: social media posts, magazines, books, mirrors, clothes, scales, apps, and foodstuff are the most commonly mentioned.

Participants describe their recovery as an assemblage of decisions, actions, coincidences, people, places, matter, and metaphors, bottom-up and top-down approaches, sharing a similar effect: participants grow around their EDs (Tonkin, 1996). Recovery feels foreign and imposed at first, but the effort of pulling away from one's EDs carves a space to explore authenticity. One participant, for example, describes the sense of discomfort while learning new coping mechanisms substituting her EDs, as a way to negotiate everyday life. Participants' various recovery processes have been visually organized to highlight similarities and connections: recovery involves practical actions, learning, reflecting, and imagining. Participants remember their recovery starting point as either a moment in time or as an evolving process, which entails emotional maturity and readiness. Recovery is something that happens or is sought: from an unexpected event (e.g., a physical illness that jeopardizes the practice of disordered eating) to participants seeking help over losing control over exhausting dieting practices.

Practical actions often follow the beginning of recovery. They are linked to one's survival, require immediacy, are context-related, and focus on setting boundaries with oneself and others. Participants mention giving up the practice of body checking by removing scales and mirrors. One participant set boundaries with her family, asking them to stop commenting on physical appearances. These actions are implemented alone or with the help of therapists, friends, and loved ones.

Learning refers to adopting, e.g., new behaviors, coping mechanisms, and perspectives to help anchor oneself out of an ED. Learning happens slowly, imperfectly, and requires practice. Learning is mediated but independent of a context. Concepts can be learned top-down or bottom-up; for example, participants describe their need to re-learn how to eat by listening to their body's hunger and satiety cues, or they mention the concept of mindful eating, learned in therapeutic settings.

Once one steps into a recovery mindset, the entire socio-material environment that once maintained EDs transforms into a living metaphor that supports one's recovery journey. One participant, for example, explains how picking up gardening taught him to see his body as an organism to cultivate rather than control. Exploring new activities or looking for metaphors in one's everyday life are actions instrumentally used for self-exploration. This phase becomes a life-long pursuit, actively sought and self-initiated until it becomes a new lens through which one sees oneself. Reflection and incorporation can happen at any moment: they require effort, a specific dedicated time, and purposeful cultivation (e.g., journaling).

A Design model for relational and material healing from Eating Disorders

The model developed from the interviews' analysis is composed of:

1. **Actions:** five non-linear phases toward crafting a new sense of self. Seciding; 2. Doing and Undoing; 3. Learning; 4. Imagining; 5. Reflecting and Incorporating, toward becoming.
2. **Elements:** human and non-human actors involved in the recovery process, such as 1. People (e.g., professionals, support networks, strangers' influences, and pets) 2. Tools and environments (removing, changing, adding); 3. Practices (material or conceptual that provide structure or distraction).
3. **Layers:** design interventions are focused on relationships between intrapersonal, interpersonal socio-cultural levels.
4. **Concepts:** the model should generate new reframing of one's experience with EDs and suggest propositions toward recovery; here are a few examples: how does food teach us to inhabit our bodies safely? How does one develop tools to learn interoceptive and proprioceptive awareness? How does one materialize fictional provisional selves?

The remaining part of the paper describes "1. Actions" to explain the model's functioning.

Actions

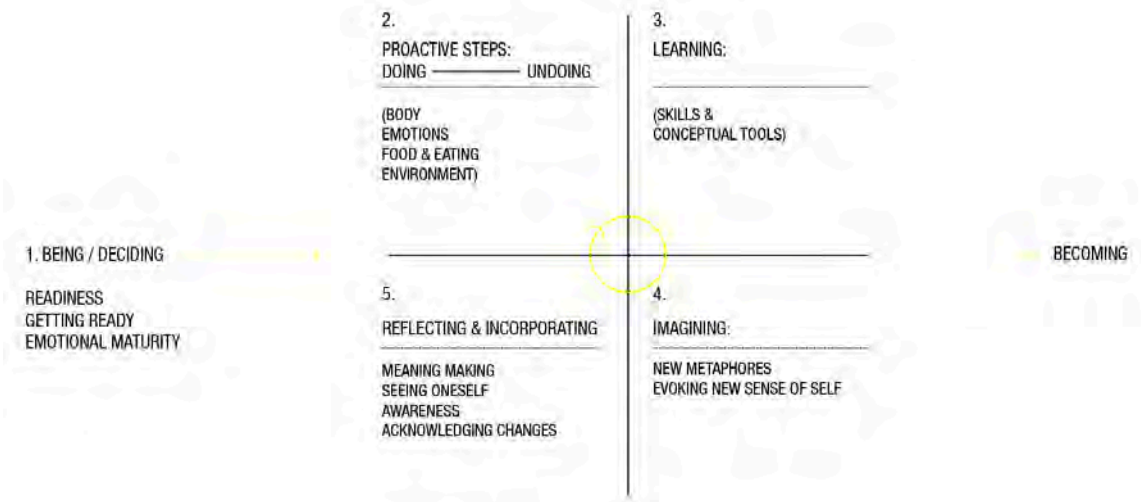

Figure 1. Actions Scheme; The five phases are displayed within a quadrant

The five phases described should serve as a guide to conceptualizing recovery design interventions that match one's current state of the disorder. Existing approaches in Design for Behavior Change, inform the interventions (Niedderer et al., 2017).

The model, for example, shares similarities with the Practice-Oriented Design approach described by Kujer (Niedderer et al., 2017): practices should be analyzed considering the elements that compose them, and interventions should focus on their reconfiguration. The model is also informed by the concept of Script and its translation into material form, as described by Latour (2005).

Designing recovery interventions should consider spontaneous bottom-up and top-down approaches informed by theoretical underpinning, as collected from the research methods. Each of these recovery approaches should be analyzed in a distributed manner to extrapolate aims, elements (humans and non-humans), and levels involved. The findings of this analysis should be translated into a script and into matter: tools, props, and contextual changes or disruptions should promote behavior change, mediate interactions and connections, and inspire new ways of being outside one's EDs.

1. Deciding

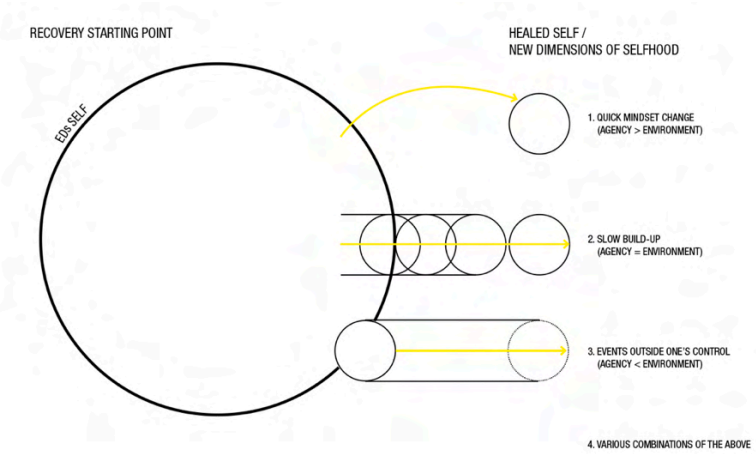

Figure 2. "Deciding" scheme

The scheme depicts four recovery starting points: one circle on the left, representing the Eating Disordered self, connects with different configurations of circles on the right. Recovery starting points are negotiated between agency and environment (Clarke, 2009), where someone's agency takes over one's environment, where agency and environment support each other, or where the environment takes over one's agency and forces the recovery process. One participant described her recovery starting point as a combination of events: a fight with a friend, loneliness, frustrations towards her life choices, and Oreos as the only form of comfort, carefully afforded the participant to lose control over her rigid dieting plan, allowed her to question the efficacy of her EDs, and to take distance from family's influences around dieting. This recovery process, for example, is a negotiation between environment and agency and touches on three different layers (one's relationship with food and the self, with family and friends, and with fatphobic cultural influences). A design intervention could provoke a careful loss of trust in one's EDs efficacy, mediated by food, relationships, and the environment, by tweaking contextual affordances and reconfiguring actions.

2. Doing and undoing

This phase follows the beginning of one's recovery process, enabling or constraining specific actions, and setting physical and emotional boundaries to allow a different engagement with one's environment. Actions are tight to one context and have immediacy qualities. Participants, for example, mention stepping away from the environment and interactions centered on the thin or athletic body and removing tools (mirrors, scales, clothes, fitness apps) that maintain one's EDs practices. Design intervention can focus on a collaborative effort in reconfiguring

environment engagement or disrupting the objects' function that supports EDs practices.

3. Learning

This phase focuses on acquiring skills around eating, listening, and re-inhabiting one's body, getting to know one's emotions and equivalent coping skills. These skills can come from medical, therapeutic, and non-therapeutic relationships. Design interventions could focus on extrapolating the program of action of theoretical or practical skills (e.g., feeling one's emotions) and inscribing them into props for practicing. These props should be designed considering the necessity of creating proper spaces, times, and easiness for repetition. These props can be developed in collaboration with the participants' therapists or support networks.

4. Imagining

This phase refers to an exercise in imagination via Speculative and Fictional Design approaches: visualizing, inspiring, enacting, experiencing, and exploring activities to deepen one's understanding until one steps into future, preferred, and healed selves. Zimmerman (2009), referring to Ibarra's (1999) concept of provisional selves, explains Design's intrinsic capacities to bring new dimensions of selfhood through objects. Speculative Design approaches can have healing properties if we compare them to narrative therapy approaches: narrative therapy operates through telling and retelling one's story to escape the dominant narrative that influences the perception of one's life, encouraging the untypical (Payne 2006). Fictional and Speculative Design materialize propositions that bridge preferred realities (e.g., a healed one) while allowing a new inquiry of the present (Wakkary et al., 2015).

5. Reflecting and Incorporating

Reflecting and incorporating are less than individual phases described above but should be included between or at the end of each phase. It refers to the capacity to recognize one's progress, safely welcome the new, reflect on changes, meaning-making, and develop new goals.

Conclusions

This exploration is in the process of being completed. The final methods will test the model's capacity to produce creative, pragmatic, fictional, and evocative design propositions, allowing a new and healed sense of self to emerge. Design reframing focuses on "providing alternatives to deeply ingrained ways of thinking" (Koskinen et al. 2011: 47): in this case, Design can be seen as possessing intrinsic healing qualities. Healing by Design is a collective effort and focuses on questioning the various relations that produce mental disorders in the first place. Recovery by Design has no single focal point but is made of a combination of interventions.

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Humanization in Oncological Health Services

A Brazilian case study

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In the health area, the focus of care has historically been on technical issues aimed at disease or illness treatment, making humanized healthcare, sometimes, a secondary position. In Brazil, the National Humanization Policy presents guidelines that guide human practice in the provision of health services.

Among the services provided by the Unified Health System (SUS) - the Brazilian public healthcare system - there is the oncology service. In addition to diagnosis and treatment, the service needs to understand the physical, cognitive, and emotional vulnerabilities of the cancer patient. In this sense, this study aims to investigate the aspects that contribute to or hinder humanized care, according to the patients' perception of an oncology service.

As a research method, a case study was carried out in an oncology outpatient clinic of the SUS in a Brazilian hospital. The data was collected through in-depth interviews with patients.

Through our results, we observed that the factors which contribute to humanized care are related to human interaction, involving affection, cordiality, respect, and empathy. The factors that make this perception difficult are associated with technical communication, bureaucracy related to treatment, and waiting time for care, which influence the experience, engagement, and well-being of the patient.

Keywords: *humanization; oncology service; service design; healthcare*

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Introduction

Humanization in healthcare arises from the need for a holistic approach to illness and has been a concern in the area for years (De la Fuente-Martos et al., 2018). The concept of health, adopted in this study, is defined as the complete state of physical, mental, and social well-being and not merely the absence of disease or infirmity (WHO, 1948). From this perspective, we believe that humanization in health is a crucial pillar to generating successful experiences, not limiting health care to merely technical-scientific issues and disconnected from ethical and human knowledge. This is because making care humanized is to reveal the values that constitute the human being as a person in a comprehensive and complete way (Pessini, 2004).

In the health area, the focus of care has historically been on technical issues aimed at disease or illness treatment, making humanized healthcare, sometimes, a secondary position. Todres, Galvin, and Dahlberg (2007) state that although technological advances and research have improved the health and well-being of patients, the human dimensions of care cannot be obscured.

Humanization is defined by some authors as an experiential process that permeates all the activity of the place and the people who work there, seeking not only to perform the technique but also to offer the patient the treatment deserved as a human being, within the peculiar circumstances, in which they find themselves at each moment in the health service (Carvalho, Paula & Moraes, 2007). Others argue that humanizing entails centralizing all health policies and actions that occur throughout the human being (Whits, 1985). In turn, Youngson and Blennerhassett (2016) define the humanization of healthcare as a state of well-being, involving affection, dedication, and respect for the other, considering the person as complete and complex. This humanized context generates experiences loaded with emotions that, if positive, tend to favor a person's organic rebalancing, affecting the immune system and helping in the healing process (Sternberg, 2009).

Considering this perspective, in Brazil, it was created the National Program for the Humanization of Assistance Hospitals (NPHAH), whose objective is to improve the relationships between professionals and users of the health service, and among professionals, the hospital, and the community, to change the standard of care provided and provide improvement in quality and effectiveness of health services (Brazil, 2001). In the program, humanization in health aims at rescuing respect for human life, taking into account the social, ethical, educational, and psychological circumstances present in every human relationship.

To reinforce human practice in the provision of health services, in 2003 Brazil established the National Humanization Policy (NHP), popularly known as HumanizaSUS, seeking to put into practice the principles of the Unified Health System (SUS) - the Brazilian public healthcare system - aimed at full access, universal and equitable-in the daily life of health services, producing changes in the ways of managing and caring (Brazil, 2004). For this, principles were established aimed at the transversality, the inseparability between care and management, and the protagonism, co-responsibility, and autonomy of subjects and groups. In addition to establishing guidelines based on reception, participatory management and co-management, ambience, expanded and shared clinic, appreciation of the worker, and defense of users' rights among others (Brazil, 2004).

The established principles and guidelines aim to act on different factors contributing to health services' humanization as: welcoming; patient appreciation and attention to global needs; establishment of good relationships; good communication; active

listening, and creation of bonds with the patient and his/her family; respect for the patient's individuality, autonomy, and particularities; spiritual needs and faith; qualification of professionals; periodic team meetings; protection of patient rights; development of recreational activities; and improvement of infrastructure in the hospital environment (Anacleto, Cecchetto & Riegel, 2020).

In this sense, humanization requires a reflective process on the values and principles that guide professional practice, in addition to providing treatment and care with dignity, solidarity, and warmth to its primary objective—the fragile patient. This approach aligns with service design where the project contemplates the entire service experience, as well as the design of the process and the strategy to deliver it (Moritz, 2005).

However, despite the initiative, the scope of SUS in Brazil involves different types of services and complexities. In addition, according to Waldow and Borges (2011), care and humanization constitute an activity that deals with the human being in situations of vulnerability. Furthermore, is important that obstacles in the use of services are eliminated, so that equitable possibilities are offered to all (Castro et al., 2011), regardless of physical or cognitive conditions, which makes humanization in health a constant challenge, given the complexity of the context, the interaction of users and their needs.

Among the services provided by SUS is the oncology service. In addition to diagnosis and treatment, the service needs to understand the physical, cognitive, and emotional vulnerabilities of the cancer patient. This is because oncological patients face barriers caused by the pathology or treatments, such as a prolonged course of the disease, other health complications, disabilities (AIHW, 2020), psychological suffering (Verhaak et al., 2005), and impact on the quality of life (Phillips & Currow, 2010). Thus, oncological care means complex care, since it involves multiple factors (Costa, Filho & Soares, 2003; Simões et al., 2021). For this reason, patients diagnosed with cancer should be treated, not merely as another cancer case, but they need to be attended to from a holistic, multidisciplinary, and humanized perspective (Costa, Lunardi Filho & Soares, 2003; Carayon & Wooldridge, 2020).

Although it is noted and recognized the importance of humanized assistance, we know that not all services and their respective professionals recognize and use it in the exercise of their profession (Silva et al., 2018). So, several barriers undermine fair and equitable access to health services as architectural/physical aspects (Santos et al., 2012; Geraldo & Andrade, 2022), technological aspects (Carayon, Hundt & Hoonakker, 2019; Geraldo & Andrade, 2022), attitudinal aspects (Hashemi et al., 2022), and informational/communicational aspects (Geraldo & Andrade, 2022). Thus, it should be important to understand this scenario in order to structure a line of care that contributes to humanized care, influencing patients' experience, engagement, and well-being. In this context, design plays a critical role in delivering healthcare and generating better experiences for patients (Swann, 2017). Therefore, this study aims to investigate the aspects that contribute to or hinder humanized care according to the patients' perception of an oncology service.

Methodology

This research followed an exploratory approach. We carried out in-depth interviews with six patients in an out-patient oncological service of a Brazilian hospital. The sample was determined by convenience and data saturation was observed in order to stop the interviews. A protocol with semi-structured question scripts was used to guide data collection. The data were obtained through primary sources, using a

direct and personal approach in the interviews. The interviews were recorded, transcribed and the data were tabulated for further analysis.

For data analysis, thematic analysis was performed (Braun & Clarke, 2014), considering the aspects of humanization perceived in the data collection from the interviews.

Regarding research ethics, the study was approved by the UFCSPA's Institutional Review Board (CAAE 55467222.5.0000.5345), complying with the Data Protection Act. The hospital also provided a term of acceptance to carry out the study.

Results and Discussion

In this section, the findings and the discussion of our research are presented.

Aspects that contribute humanized care

In this first section, we present the aspects that contribute to humanized care according to the perception of patients in an oncology service. From the interviews carried out with cancer patients, we identified different aspects that contribute to the humanization of care, which were grouped into two categories: interaction between health professionals and patients; and protection of users' rights.

Humanization was reported mainly in situations of patients' interaction with the oncology service (medical, nursing, and administrative professionals), defined as good. According to the interviewees, the way the service team welcomes the patient with empathy, cordiality, affection, and sympathy conveys security and tranquility. The care with which the nurse welcomes the patient facilitates coping with the disease, reducing anxiety and stress. In particular, the humanized reception carried out by the medical care team generates a relationship of trust and respect, increasing the feeling of well-being and generating a positive experience, aligned with Youngson and Blennerhassett (2016), and Hashemi et al. (2022).

Interaction between cancer patients was also reported in the interviews. According to the interviewees, the interaction between patients is positive and generates a sense of belonging as they share experiences and exchange information in relation to their situations as cancer patients. Humanization in this case is reported by the form of reception, with demonstrations of affection and empathy during the time of treatment. Although there is no mechanism in the health service that encourages this type of interaction, it happens as a form of support among patients, which provides the creation of affective bonds and a more hopeful environment, aligned with Hashemi et al. (2022).

Humanization was also perceived in aspects related to the defense of the rights of cancer patients. Respondents reported that the approach taken by medical professionals to communicate the diagnosis was objective and clear, making them aware of the real situation in which they found themselves. Communication is defined as one of the pillars for the implementation of the NHP, favoring health professionals to understand the patient, their needs and uniqueness, as well as provide the patient with access to information about their diagnosis, treatment, and prognosis (Brazil, 2004).

In addition, according to the interviewees, despite the technical language used in the description of the diagnosis, the medical professionals sought to reassure them, presenting the possible treatments available through the SUS as well as advising them on the most recommended treatment plan for their condition. At this point, it is

observed that despite the humanization guidelines recommending shared decision-making, this ended up being the responsibility of the medical professional, since the interviewees did not feel safe in giving an opinion and perceived the medical professionals as qualified to decide the outcome. However, for the interviewees, keeping them informed about the care provided, helping in decision-making, and coping with the difficulties encountered during treatment are important factors to promote engagement, aligned with Geraldo and Andrade (2022).

Another aspect reported refers to the access of cancer patients to services and support networks, such as leagues. According to some of the interviewees, the role played by the league is fundamental, as it acts in a complementary way to the treatment of the disease, providing support for financial, emotional, and social issues. In addition, patients perceive that the league provides comprehensive care, considering all its characteristics, context, mental health, and well-being, as pointed out by Whits (1985).

One interviewee pointed out the importance of the Ombudsman service, established in SUS, as a way of reporting negative and positive situations without the need for identification. Qualified listening is another pillar of the NHP (Brazil, 2004). In addition, this type of technological resource provides the opportunity to manifest different situations without exposing the patient to any type of embarrassment, aligned with Carayon, Hundt and Hoonakker (2019).

In short, our results showed that the factors which contribute to humanized care are related to human interaction (patient-health professionals), involving affection, cordiality, respect, and empathy. And less relevantly, the defense of users' rights, with regard to diagnosis and treatment options, as well as a support network and manifestation channels.

Aspects that hinder humanized care

In this second section, we present the aspects that hinder to humanized care according to the patients' perception of the oncology service. From the interviews carried out with cancer patients, we identified different aspects. These aspects were categorized into aspects related to the service and aspects beyond the service. The origin of these aspects is different, but both impair the patients' perception of humanized care.

Regarding the aspects related to the service, two thematic categories were identified, from the data of the interviews: the relationship between health professionals and patients; and ambiance. Concerning the relationship between professional and patient, the aspects that hinder to humanized care, according to the patients, are bad mood of the health professional in dealing with the patient, technical communication between healthcare professional and patient (without establishing good communication, and limited active listening), standardization of care (not taking into account different needs), and overload of the service professional, making the service less empathetic and enlightening. It was noted that these aspects negatively influence the perception of humanized care, even more taking into account the vulnerability of cancer patients, who require personalized care according to their needs, as pointed out by Costa, Lunardi Filho and Soares (2003) and Hashemi et al. (2022). These patients are so fragile that their perception of humanized care goes far beyond a good diagnosis; it requires attention, care, concern, dialogue, and the establishment of bonds with the health professionals, as pointed out by Youngson and Blennerhassett (2016).

Regarding the ambiance, the interviewees indicated aspects that make it difficult to perceive humanization in the health service. Some patients struggle with mobility and locomotion barriers. They pointed out that the institution and the service do not

provide enough structure for everyone to use them. The lack of ramps, adequate signage, and resources that address individualities were identified as factors that influence the perception of humanized care. In addition, patients indicated that the service space is too small. When they are not feeling well or receive bad news from the doctor, their individuality is compromised, as all the other patients at the reception are observing what is happening. This is related to the concept of humanization brought by Carvalho, Paula and Moraes (2007), in which humanization is more than technical aspects related to care, but other aspects of this process, as pointed out by Santos et al. (2012), and Geraldo and Andrade (2022).

The aspects beyond the service that hinder humanized care are related to patients' perceptions of delay to receive care, waiting in lines, wrong entrance doors, search for other services in the hospital, etc. These are issues that generate discontent, but that are not necessarily related to the service, but rather to the Brazilian health system and its bureaucracies. The aspects that appeared the most in this category were related to SUS' bureaucracies and lack of clear information. Regarding the bureaucracy, patients reported confusion about the flows to be followed in the service after the consultation and during the treatment, different information for patients to assimilate, and the need for a companion support to understand the processes - which was not always possible. These aspects are related to the healthcare system bureaucracy, but also to the lack of clear information about the bureaucratic processes involved in care. Patients receiving oncological care in the institution sometimes did not know that they could not receive other treatments there. Instead, they should seek public assistance at other gateways, such as basic health units, for example. That is, this is part of the flows of SUS, but which are not clear to the patients who use it, contrary to what was proposed by Santos et al. (2012), and Geraldo and Andrade (2022). Therefore, discontents related to these aspects are not directly related to the oncological service, but to the health system in general. These less humanized aspects impact the patient's quality of life throughout their treatment (Phillips & Currow, 2010). In this context, design plays a critical role in delivering healthcare and generating better experiences for patients (Swann, 2017; Moritz, 2005).

In summary, the factors that make this perception difficult are associated with technical communication, bureaucracy related to treatment, and waiting time for care, which influence the experience, engagement, and well-being of the patient.

Our results are summarized in Figure 1.

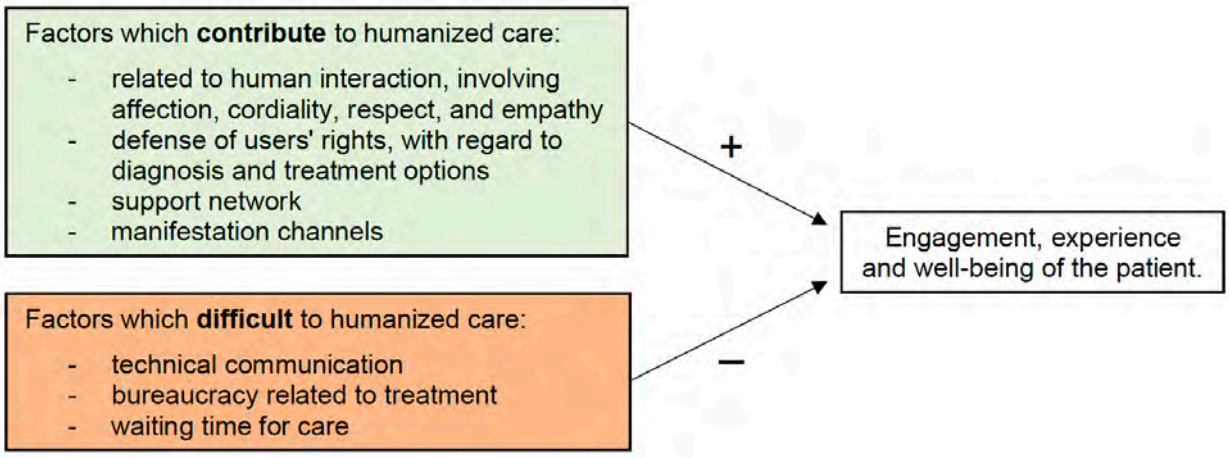

Figure 1. Factors which contribute to or make difficult humanized care

Conclusion

The humanization of healthcare entails affection, dedication, and respect for others, considering the person as a complete and complex being, to generate positive experiences, engagement, and well-being for cancer patients. This study aimed to investigate the aspects that contribute or hinder humanized care according to the patients' perception of an oncology service.

As a research method, a case study was carried out in an oncology outpatient clinic of the SUS in a Brazilian hospital. The data was collected through in-depth interviews with patients.

From our findings, we observed that the factors which contribute to humanized care are related to human interaction (patient-health professionals), involving affection, cordiality, respect, and empathy. The factors that make this perception difficult are associated with technical communication, bureaucracy related to treatment, and waiting time for care, which influence the experience, engagement, and well-being of the patient. In this sense, according to the perception of cancer patients, the health service seeks to implement the principles and guidelines recommended by the NPH but has points of improvement that still need to be further designed. In addition, the results of the study indicate that the search for the humanization of care makes patient treatment less traumatizing as it encompasses a look at the different dimensions and the patient's global needs, according to Anacleto, Cecchetto and Riegel (2020). In this way, it reiterates the importance of the NHP in directing and implementing best practices in humanization of care in the context of the process health disease of users with cancer, as well as, points to service design as an approach that can contribute to these projections (Swann, 2017; Moritz, 2005).

This study has limitations regarding the possibility of being generalized, as it is a case study. Aiming at new studies, research with a quantitative approach is suggested, as well as comparative studies. We understand that the study seeks to contribute to the improvement of health services as it highlights the importance of humanization from the perspective of the patient. In addition, based on the results found, it is possible to design services that encourage aspects that contribute to humanization and minimize those aspects that make humanization difficult, aiming to generate better experiences, engagement, and well-being for cancer patients.

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Empowering Patientship

Exploring the conceptions of patient-centeredness via definitions and cases

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Socio-technical transformations in digital technology and healthcare have enabled the growth of patient-centered care models. Furthermore, the global pandemic highlighted the essential role of design in integrating these innovations with human-centered design approaches and the development of products, services, and caregiving systems to enhance patients' lives. Our aim is to highlight the significance of humanizing healthcare by identifying emerging practices in two regions to develop a structured account of the range of approaches that can empower patients and transform the culture of caregiving systems. As a preliminary work, we review definitions of patient-centered care from health-related literature and share cases in which patient-centered design is a key factor. We provide a thematic analysis of aspects that constitute patient-centered care and graph different perspectives on patient-centric approaches in both domains. We compare and contrast the perspectives of patient-centered care to patient-centered design. Our goal is to provide a theoretical basis for patient-centeredness that can offer a shared ground and language to facilitate interdisciplinary collaboration, and expand the conception of patient-centeredness, emphasizing collective wellbeing in addition to individual health.

Keywords: *healthcare design; patient-centeredness; empowering patientship; humanizing healthcar*

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Introduction

The last decade has been characterized by socio-technical transformations in the field of healthcare, fostering the growth of patient-centered care models in clinical research and policies. Concurrently, the global pandemic highlighted the essential role of design in integrating these technological and social innovations with human-centered design approaches and the development of product-service systems to include patients in the process of medical care. However, there is a dearth of studies that systematically explore the theories of patient-centeredness in relation to the constellation of healthcare and design practices, and investigate the significance of humanizing healthcare.

In this paper, we present a project titled “Empowering Patientship,” in which design scholars from research centers in Europe and the United States collaborate to study patient-centric design cases. The project was initiated in 2017 by Polifactory, Department of Design, Politecnico di Milano, in Milan, Italy. Its goal was to build a theoretical framework and a structured methodology in order to identify, map, and systematize innovative product-service practices and illustrate the ongoing patient-centric transformation of the healthcare field in Italy. This research activity was later expanded to include agents who are central to this transformation: patients and their associations, caregivers, and varied healthcare providers. This research has ultimately made it possible to shape and graphically view the agents who are involved in healthcare in a holistic manner, via maps that present the design process underlying the development of healthcare services and products and the three main areas of the Italian healthcare system: patient & caregiving system, healthcare & research system, and the system of making, manufacturing, new entrepreneurship.

Since 2022, a collaboration has begun with the Center for Design at Northeastern University, Boston, Massachusetts, USA. The center is a platform for interdisciplinary design research in collaboration with healthcare organizations, healthcare design firms, and other healthcare experts from diverse fields in Boston. The Milan and Boston teams are building on the previously mentioned research to explore the emerging role of patients and caregivers as user-innovators within design processes. Specifically, we are collecting and mapping patient-centered projects in two regions and conducting a literature review of definitions of patient-centeredness. Our goal is to develop a systematic account of the range of approaches that can empower patients, identify potential opportunities to humanize healthcare, and develop future strategies for designers to transform the culture of caregiving systems.

In this paper, we share our preliminary findings on definitions of patient-centeredness, addressing the fundamental research question, “What is patient-centeredness in healthcare and design?”. In the following section, we will share the diverse meanings and perspectives that comprise the concept of patient-centeredness. These definitions were collected through a literature review of healthcare and design, as well as a collection of real-world cases.

Definitions of Patient-Centeredness

Patient-centeredness in healthcare

In order to study the diverse dimensions of patient-centeredness we conducted a literature review across different disciplines (oncology, emergency medicine, pediatrics, diagnostics, healthcare information technology, psychology, and care facility organizational structures) focused primarily on systemic reviews from 2012 to 2022 on PubMed.

We found 10 main areas of overlap (Figure 1), with *listening to patients* at the center (Davis, Schoenbaum, & Audet, 2005; Kvåle & Bondevik, 2008; Saha, Beach & Cooper, 2008; Pinto et al., 2012; Hoerger et al., 2013; Rathert et al., 2015; Truccolo et al., 2016; Gabutti, Mascia, & Cicchetti, 2017; Fix et al., 2018; Mitchell et al., 2020; Abdullahi Yari et al., 2021; Geerts et al., 2021; Leidner et al., 2021; McGrady, Pai, & Prosser, 2021; Wittenberg et al., 2021). Systematic reviews viewed patient-centeredness as taking into account a *holistic view of the patient* and incorporating their wishes and capabilities (Saha, Beach, & Cooper, 2008; Hoerger et al., 2013; Rathert et al., 2015; Fix et al., 2018; Cotta Ramusino et al., 2021; Geerts et al., 2021; Leidner et al., 2021; McGrady, Pai, & Prosser, 2021; Wittenberg et al., 2021). This leads to the creation of *individualized care plans* (Mead & Bower, 2000; Saha, Beach, & Cooper, 2008; Pinto et al., 2012; Shankar, Bhatia & Schuur, 2014; Truccolo et al., 2016; Fix et al., 2018; Hohmann et al., 2020; Cotta Ramusino et al., 2021; Geerts et al., 2021; Leidner et al., 2021; McGrady, Pai, & Prosser, 2021; Wittenberg et al., 2021).

Most reviews stressed *honest sharing of information* with the patient and taking efforts to convey medical knowledge and options in a way that patients can understand and make judgments upon (Davis, Schoenbaum, & Audet, 2005; Kvåle & Bondevik, 2008; Saha, Beach, & Cooper, 2008; Pinto et al., 2012; Hoerger et al., 2013; Shankar, Bhatia, & Schuur, 2014; Rathert et al., 2015; Truccolo et al., 2016; Mitchell et al., 2020; Abdullahi Yari et al., 2021; Cotta Ramusino et al., 2021; McGrady, Pai, & Prosser, 2021; Wittenberg et al., 2021). There are fields, such as oncology, that are divided in regards to the quantity and timing of information delivery due to the impact disclosure results could have on the patient. (Mitchell et al., 2020; Cotta Ramusino et al., 2021). As many papers place strong emphasis on *the patient's psychological state* within their definition of patient-centeredness (Mead & Bower, 2000a, 2000b, 2002; Pinto et al., 2012; Rathert et al., 2015; Truccolo et al., 2016; Fix et al., 2018; Mitchell et al., 2020; Cotta Ramusino et al., 2021; Geerts et al., 2021; McGrady, Pai, & Prosser, 2021), at the expense of honesty, there is a divide in the literature where the balance lies.

A dominant concept in literature is that the doctor and patient should *share power in the collaboration of a healthcare plan*, though there is a divide on what this entails. Some believe this collaboration is a way to elicit buy-in from the patient for the doctor's prescribed course of treatment, but avoid giving the patient real power over their treatment choice. Many doctors view giving patients the option to make what they perceive to be a suboptimal choice as a violation of the doctor's oath to do no harm (Davis, Schoenbaum, & Audet, 2005; Saha, Beach, & Cooper, 2008; Pinto et al., 2012; Hoerger et al., 2013; Rathert et al., 2015; Truccolo et al., 2016; Fix et al., 2018; Abdullahi Yari et al., 2021; Geerts et al., 2021; Leidner et al., 2021; McGrady, Pai, & Prosser, 2021; Wittenberg et al., 2021). Others believe in *an iterative communication process* in which the patient is informed of the current status of their condition and treatment plan, alternatives and tradeoffs throughout the care process, and being actively involved in requesting changes in care (Mead, Bower, & Hann, 2002; Davis, Schoenbaum, & Audet, 2005; Truccolo et al., 2016; Gabutti,

Mascia, & Cicchetti, 2017; Hohmann et al., 2020; Geerts et al., 2021; Wittenberg et al., 2021).

On an organizational level, patient-centeredness is viewed as *optimizing the overall experience of patients* from the moment they walk into a facility (Fix et al., 2018). This entails restructuring hospitals and care facilities to be oriented toward individual patients and their unique needs rather than organized in specialist departments and primary physicians (Saha, Beach, & Cooper, 2008; Rathert et al., 2015; Gabutti, Mascia, & Cicchetti, 2017) and providing *continuity of care* (Davis, Schoenbaum, & Audet, 2005; Saha, Beach, & Cooper, 2008; Rathert et al., 2015; Gabutti, Mascia, & Cicchetti, 2017; Hohmann et al., 2020; Geerts et al., 2021; Leidner et al., 2021).

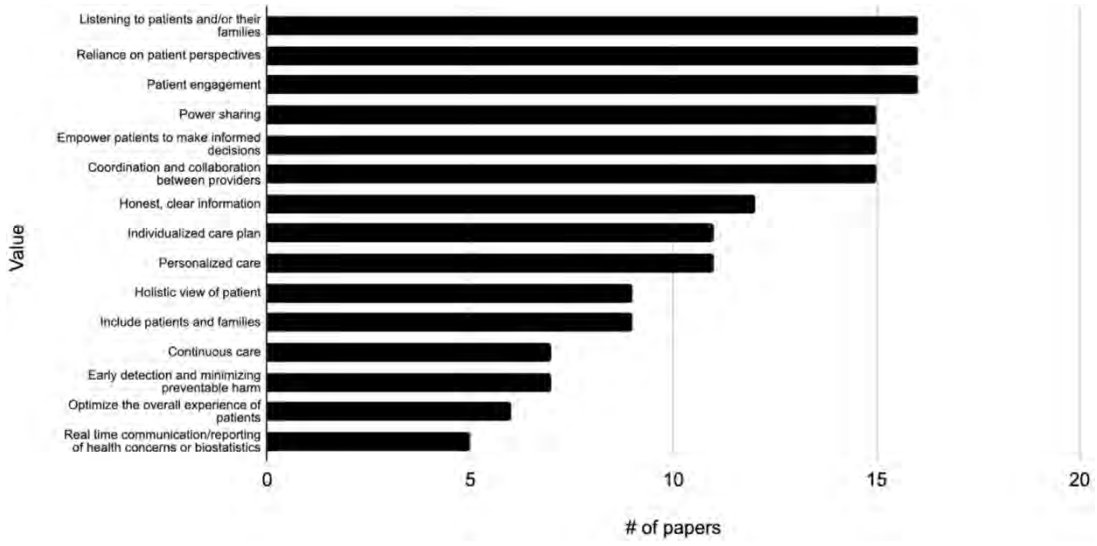

Figure 1: Patient-centered care definition aspects collected from PubMed.

Patient-centeredness from collected cases

We have also reviewed cases from existing projects to distill concepts that convey patient-centeredness as reflected in practice. The data set includes 60 cases in the greater Boston area. The most prominent theme (16 cases) was *early detection and minimizing preventable harm* amongst patients. A number of projects were designed to identify and reduce patients' safety threats, prioritizing patient outcomes. Further, designs to *track biostatistics in real-time* and *extend digital reach* allow physicians the opportunity to make timely interventions and mitigate patient risks. Digitizing the care management experience affords a shift from intermittent to *continuous care,* in between traditional care visits, which seemed to be a priority in eight cases.

Such digitization helps to promote another critical component noted in the cases, *coordination and collaboration* between the entirety of the patient's care team to provide holistic care and ensure a positive overall patient and provider experience. Coordination and collaboration was, in most cases, also extended to the families and support systems of patients, acknowledging the integral role that these members play in patients' health and patient-centered care. Partnership of patient, family and care team enables *personalized patient care* that ideally reflects patient wants, needs and preferences, another theme that occurred in 13 cases.

Lastly, the *empowerment of patient*s to actively participate in their own care and make informed decisions for their health was also mentioned in 12 cases. Such

projects utilized design that served to educate patients, allow easier access and control of their health information, as well as enhance continued communication and support from providers, with the goal of enabling patients to control their own individual journeys.

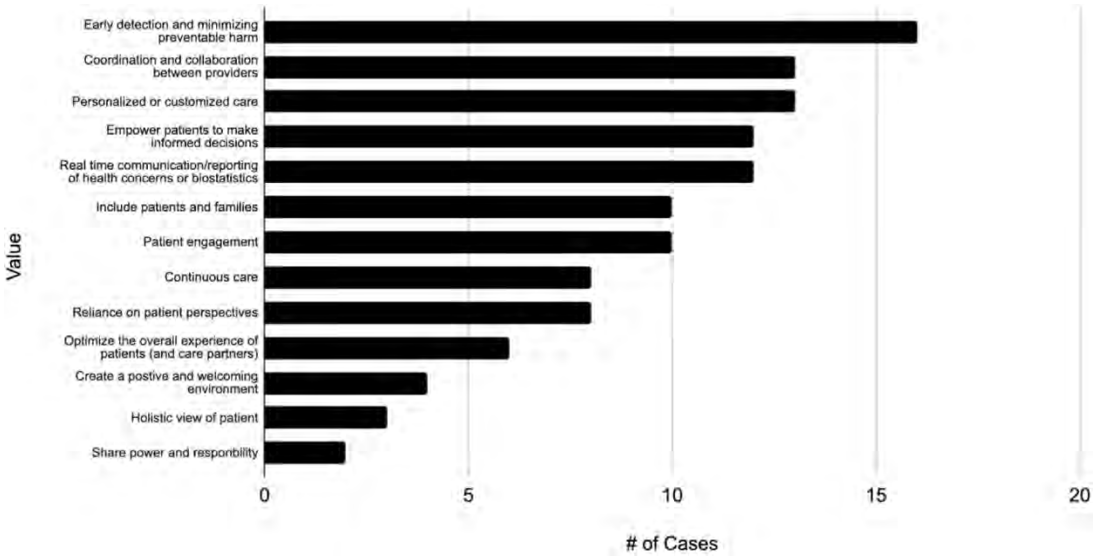

Figure 2. Mapping of the definitions collected from real-world cases

Patient-centeredness in design

Inclusion of patients and more diverse agents has profoundly changed the design of cure and care activities, pushing the boundaries of design as a discipline, profession, and attitude towards healthcare organizational models. At the same time, it assisted in the rise of a new series of practices and experiences where patients pro-actively contribute to co-produce, co-create and co-design solutions to their often-unmet needs. We can define this happening as *patient innovation*, in other words, an array of open, collaborative, and participatory products, services, processes, and systems generated by their end-users (Bogers et al., 2010; Von Hippel, 2009, Ciuccarelli, 2008). As a result, design becomes a tool for progress toward new healthcare paradigms (DeMonaco et al., 2019).

Contemporarily, innovation within healthcare ecosystems also means measuring and analyzing the impact of the innovation led by patients, caregivers, and caregiving systems (Zejnilović et al., 2016; Gambardella et al., 2017). Furthermore, it often means a holistic understanding of all the relationships which rule the connections between transformation mechanisms and bottom-up innovations (Keinz et al., 2012; Trott et al., 2013). As a result, a new role for design arises, to integrate and align the different actors' perspectives while co-creating value (Pereno & Eriksson, 2020; Sangiorgi et al., 2020; Vink et al., 2021). Here, design is the result of the activity of new creative profiles (i.e., citizens, makers and ultimately patients) who alter the politics of the system of production, emphasizing the importance of co-design and co-creative approach in the design of healthcare services, products, and ecosystems (Maffei et al., 2022).

Exemplar Cases

The understanding of the concept of patient-centeredness and its contextualization in design provides us with the coordinates to map and analyze services in healthcare in which the participation of the patients is clearly identifiable and the contribution of design is recognizable in the implementation of tangible and intangible elements. To highlight a few emerging themes from the definitions of patient-centeredness, we introduce two healthcare design cases from 100+ samples in Milan and Boston.

Co-design + Listening to patients and/or their families

TOP! and Say Eye are open source co-designed eye tracking softwares developed by Open Dot, a digital fabrication lab, and TOG Foundation, an NGO working on rehabilitating children. These two entities collaborated in the development of tools to enable children with cognitive/motor impairments to communicate with their eyes, thus creating new therapeutic activities. The co-design process involved Domus Academy design students and TOG's clinical staff working together to identify different ways the eye-tracking software might support communication and learning. After the initial research phase and the design of prototypes, the project team involved children's families in co-design activities to ensure that the softwares would address real, specific problems in the therapeutic journey. OpenDot asserts two markers identified above of patient-centered care: a focus on patient needs, and patient involvement in the design work.

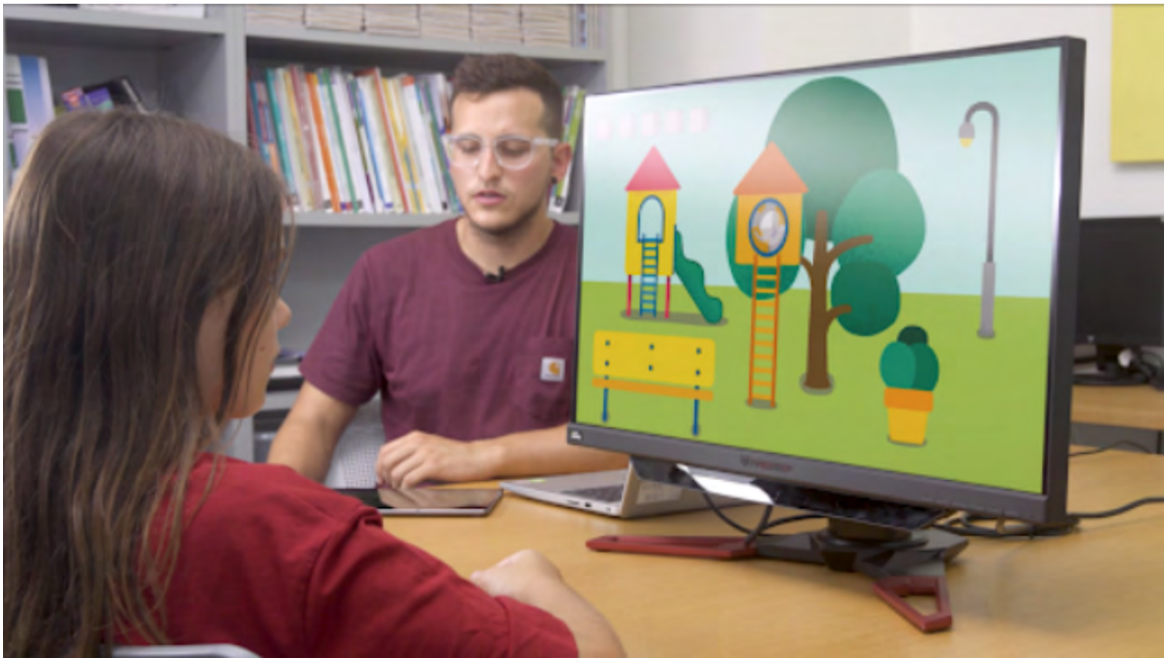

Figure 3: Top! game session. Taken from: https://medium.com/@OpenDot_fablab/play-and-eye-tracking-for-child-rehabilitation-19f89683492a

Figure 4: A co-design session between designers and the families of the patients. Taken from: https://medium.com/@OpenDot_fablab/play-and-eye-tracking-for-child-rehabilitation-19f89683492a

Holistic understanding + Continuous care that coordinates patients, families, and providers

iHealthSpace is a patient engagement platform designed by Massachusetts General Hospital to create a more personal and collaborative healthcare experience for patients and their care team. iHealthSpace provides a connected customized virtual space that empowers patients to contribute to their healthcare with the support of their family, friends, and care providers, to reduce the fragmentation imposed by organizational boundaries and put the patient front and center. Through understanding health and workflow needs from a patient perspective, iHealthSpace is designed to optimally support patients in tasks to assess their current state of health, manage problems, and prevent medical complications.

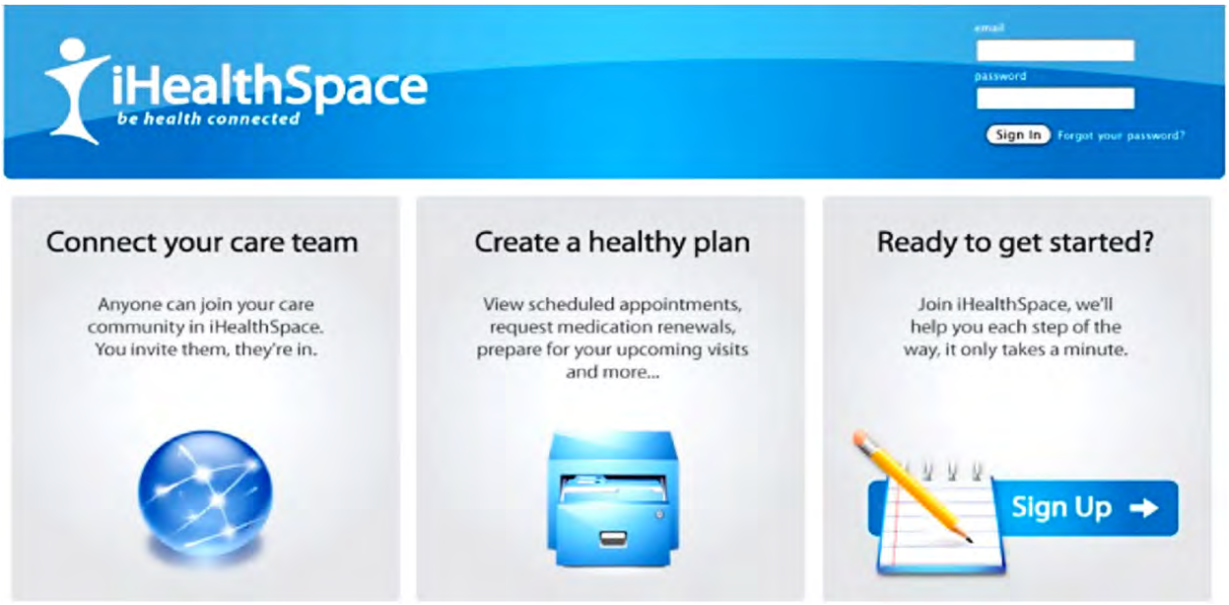

Figure 5: iHealthSpace main page (Chung et al., 2011)

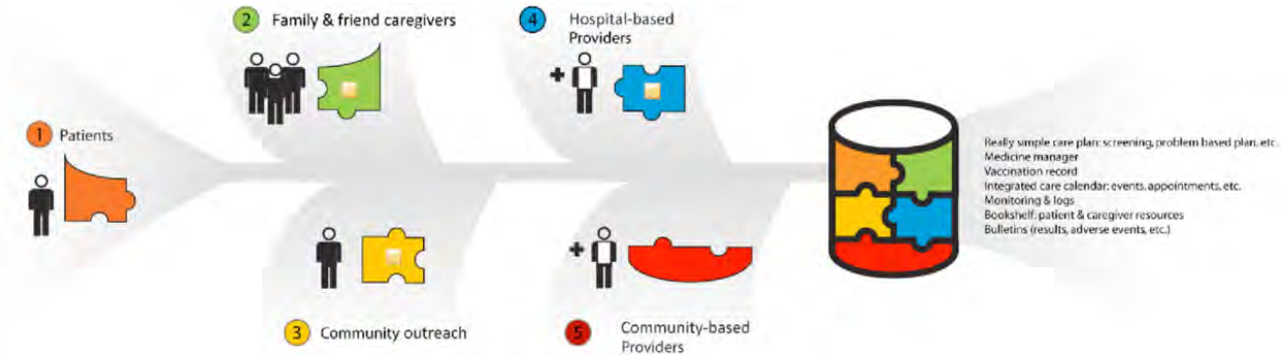

Figure 6: Communication and coordination among multiple agents in the iHealthSpace (Chung et al., 2011)

Discussion and future directions

One key differentiating factor between the *care* process and the *design* process is that the design process holds more varied opportunities for involvement by patients, allowing room for accommodating the diverse needs of people with different conditions. For patients, *care* is something that happens *to* patients, oftentimes intimately, where design is characterized by a more remote and reflective relationship. Opportunities for involvement in patient-centered *design* might allow the patient to assume control or partnership with designers to determine how the design unfolds. In healthcare design contexts, co-design practices offer opportunities for involvement throughout the lifecycle of the project and can range from a consultative role of *patient engagement*, an example could be asking patients to validate a design, to *patient participation*, where patients are involved in iterative discussions over the design process, to *co-production*, where patients are deeply involved throughout the entire lifecycle of the design process. In this preliminary analysis, key to understanding the different centerings of patient-centered design and patient-centered care is a richer understanding of involvement, and how the patient is implicated in each process.

In this preliminary analysis, we found some disparities of note between the assertions of patient-centered care in the literature, and the practices of patient-centered design as materialized in the cases. Several aspects of patient-centered care that were quite dominant in the literature were less well represented in the cases of patient-centered design. Most notably, *listening to patients and/or their families* — a key aspect in the literature — was rare in the cases. Several other prominent aspects in the literature, *reliance on patient perspectives*, *patient engagement*, and *power-sharing* were much less prevalent among the cases. Some possible arguments for this variance could be that an insufficient number of cases have been surveyed, or that there is a particular bias in the selection of cases from the Boston area. We believe it more likely, however, that these particular elements rely more upon the social cohesion of the doctor ⇔ patient relationship, and it is more difficult and perhaps also less desirable to delegate these aspects to objects. This seems to be a likely conclusion, taking the *listening* aspect as an example. The current state-of-the-art of voice-to-text translation and natural language processing does not well support objects that *listen*.

Some aspects of patient-centered design that were prominent among the cases were not as prominent in the literature of patient-centered care. Based on the team members' expert knowledge of design, we would argue that a likely case for this discrepancy is that the cases emphasize patient-centered aspects that software or other designed artifacts are likely to handle well. Essentially, certain tasks are

easier to delegate to software and digitally-enabled objects. *Early detection*, *coordination and collaboration between providers*, *personalized care*, the *inclusion of patients & families*, *continuous care*, and *experience optimization* are all aspects of patient-centered design that have a significant history of support in interaction and service design practices. Further, these are aspects of care practice that can be effectively achieved through the exchange of various data.

Based on our continuing research findings, we will collect more cases and identify key factors and patterns that constitute patient-centeredness to create a map of the existing different perspectives. Our analysis will include intervention points in the design processes, disciplines and agents, and philosophical backgrounds. We will develop a holistic vision encompassing the preliminary considerations from this review on definitions. First, there is the need to analyze and merge concepts belonging to domains that are not strictly design related. Secondly, our exploration urges us to explicitly include the caregiver and caregiving system together with the patients. This also entails considering in the design activities the value created by the complex formal and informal relationships among the diverse agents involved. Our ultimate goal is to develop a framework of patient-centeredness, a metric for evaluation, and identify opportunities and strategies to humanize healthcare design.

Conclusion

This project will contribute to the field of design by delineating a theoretical basis for patient-centeredness with a goal of providing shared ground and language to facilitate interdisciplinary collaboration. We aim to explore the future of healthcare and expand the conception of patient-centeredness, emphasizing the collective wellbeing of the community and various publics in addition to individual health. This framework will contribute to inclusive design by more clearly articulating the positioning of people with diverse health conditions at the center of the healthcare system and providing care in their everyday life settings to accommodate different needs. The World Health Organization (2016) described people-centered care as healthcare system that supports "*the comprehensive needs of people rather than individual diseases, and respects social preferences (...) encompassing not only clinical encounters, but also including attention to the health of people in their communities and their crucial role in shaping health policy and health service*" (p2). The success of a patient-centered design can precipitate substantial shifts at both the production and policy level, inducing organizations to translate diverse patients' and actors' design contributions into reality. This crucial change has consequences for the role of Design as a discipline and its evolution, bringing novel perspectives on the meaning of inclusiveness in healthcare.

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Track 3. Inclusive Design Applications

Environment and social impact

Fashion and dress

Track 3. Inclusive Design Applications

Mobility

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Access Denied

Decoding barriers to accessibility in market streets of New Delhi

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Urban India is kinetic and constantly evolving with its deep-rooted histories and cultures, struggling to strike a balance with the ever-changing demographics, disparities, demands and supplies.

Within this palimpsest of layers and its chaos, **accessibility** serves as a grave urban issue that needs to be catered to. The undertaken research addresses accessibility in public spaces for one such user group, i.e., differently abled who are at the forefront of those who face this problem. Imagining the daily routine of a differently-abled in the public realm is a struggle where it's challenging to go from one place to another, which dissuades their independent mobility.

Thus, the research assesses the state and suitability of two market streets in New Delhi (Hauz Khas Market and Khan Market) for people with motor and vision disabilities by documentation of the visible and invisible barriers faced at the scales of wayfinding, market premise and threshold spaces; through means of an accessibility checklist that is derived from the existing guidelines in India.

There are various design solutions and strategies available in the public realm made with ample efforts to ensure that they are integrated and harmonised to cater to all user groups. But, assessment of the market streets with respect to the necessary space requirements to be followed as per the guidelines in the chosen context for differently abled reveals gaps between the ideal and existing scenario.

Keywords: *accessibility barrier documentation; independent mobility and accessibility; Indian market streets; inclusive design guidelines*

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Introduction

> *"Disability is not just one health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives." (World Health Organisation, n.d.)*

Disability is an often disputed notion that has complex dichotomies attached to it. As the definition above provided by the World Health Organisation also suggests, it is heavily dependent on the societal norms and prejudices of what one views as an ability or disability. It is rather a societal imposition that views the physical, mental and cognitive differences in human beings as being 'different' as the limitation present due to the non-inclusive ableist[1] society.

Disability in the realm of architecture is viewed as an afterthought to design. There are various barriers faced by the differently abled in public spaces, which serve as a hindrance to accessibility from one place to another. Enablement of design solutions and guidelines inclusive of the differently abled in public streets can lead to their social inclusion and independent mobility.

The non-availability of physical infrastructure especially in public spaces forces wheelchair users and people with vision disabilities to be dependent on the so-called abled for the rest of their lives. **Thus design holds this responsibility to create an equitable and universal urban environment.** There is an existing knowledge base regarding design solutions in public spaces to create an accessible environment in the form of design guidelines, but the actual state of the markets is far from ideal. Thus there is a need to document the existing state of markets vis-à-vis differently abled and their space requirements, which serves as the gap between what should be there versus what is there. Thus, the research aims to normalise daily mobility and accessibility of differently-abled people in public spaces such that they have equal access to spaces, reducing their dependency on others and empowering them through design.

Disability, Design and Public Spaces

Defining Disability vis a vis Design

Anthropometrics is a crucial factor that shapes up building proportions in the realm of design and architecture. Taking the 'average human' as the measure, the buildings are shaped according to humans rather than vice versa.

> *Thus there is a dire need to question who we imagine as the end-users of spaces, who is being left out, and why.*

As design students, we study anthropometry in our education where fundamental human dimensions and spaces required by the average human are seen as standards for designing spaces. Adding to the rigidity of standards and the *modular man* that uses an idealistic human body as a measurement, we disregard 'differently abled' as a section of the society that is not a part of the 'normal' end-

[1] Ableism - societal prejudice against people with disabilities.

user group. Thus disability in the design education system fails to be embedded properly to be inclusive because the standard itself, which is used as the average, is flawed as it disregards the differently abled. We hardly envisage differently abled beyond the regulations of wheelchairs, as humans who should have an equal right to spaces. The concept of inclusive design is limited as a regulatory box to be ticked, disregarding its generative impetus in the design discourse.

Designers tend to create an order or system of things with 'obedient bodies' following predetermined circulation paths and occasional ramps creating vistas and aesthetics. *But what and for whom is a design-centred round?*

The human being is not a stereotype, but the body shape and size is considered to be a stereotype due to various societal assumptions. To understand the violence inflicted by design of spaces for differently abled, let's look at the following terms that deem one as 'different.'

Ability - skill to do something

Inability - the state of being unable to do something

From the terms above, there is a need to question whether inability is limited to the handicap faced by a differently-abled or the physical environment dissuades one from being able enough to do something. In India, *20 million* people are differently-abled, which means *2.1%* of the population has various disabilities (Census of India, 2001). These physical and sensory disabilities get further amplified with non-accessible public spaces, which take away their independence to reach from one place to another. The differently abled are marginalised into various special homes, day-care centres, and schools which doesn't lead to a socially-inclusive solution but rather a disabled-centric design approach. For example:

- a school **for** differently abled

- a house **for** differently abled

The underlying approach in the statements above is to design a space for the differently abled, which creates a 'special' physical environment accessible by them, but the need of the hour is to design spaces that are **inclusive of** the differently abled. Thus it is necessary to envisage public spaces and their designs as inclusive, i.e., a focus on being universal instead of catering to separate needs. By undertaking an inclusive instead of an exclusive approach towards design, no section of the society will be left out or classified as different.

Differently Abled and Public Spaces

> *"A public space refers to an area or place that is open and accessible to all peoples, regardless of gender, race, ethnicity, age or socio-economic level." (UNESCO,2017)*

One of the most commonly accepted definitions of what we consider a public space illustrates that it should be equitable and usable by all in the ideal scenario. But there is a clear gap between the theoretical construct of what we consider a public place and the reality, especially in the Indian context.

There is an existing knowledge base in India regarding barrier-free design in specialised schools and NGOs for the differently abled. With the changing building by-laws, public buildings and MNCs are making conscious efforts to provide at least the bare minimum of ramps and lifts for the differently abled.

But beyond these buildings, the 'public spaces' are left to their own fate.

The non-availability of adequate physical infrastructure, especially in public spaces, dissuades people from independently accessing any place. Rather than the destinations in itself, the journey undertaken from one's dwelling to reach the destination is more detrimental due to broken sidewalks and unavailable facilities, which forces a differently-abled to be dependent on someone else for mobility.

Design Considerations

Anything that prevents people with disabilities to independently traverse and take part in society because of their disability can be termed as a **barrier**. The most commonly known barriers to accessibility are as follows:

1. Physical Barriers: Barriers that arise due to inadequacy of physical infrastructure such as uneven walkways, lack of accessible elements such as kerb ramps, auditory information, inappropriate widths, etc.

2. Information Barriers: Barriers that dissuade people from understanding the available information and directions such as absence of auditory information, braille signage, large prints, etc.

3. Social Barriers: There are a number of societal prejudices in India faced by people with disabilities such as deeming a disability to be a personal tragedy or punishment for any past wrongdoing to name a few. They are viewed to be 'different' due to physical handicaps, which leads to their social exclusion.

This further leads to various psychological barriers for persons with disabilities as they feel insecure in traversing independently due to the discerning behaviour of people, especially in public spaces. Thus both these visible and invisible barriers lead to creating a non-accessible environment for the differently-abled.

A **barrier-free environment** enables independent access for all without a need for assistance in their daily routine and activities such as employment, leisure, buying goods, availing services, etc.These barriers are not just faced by people with vision or motor disabilities but also elderly people, people with hearing disabilities, pregnant ladies, and many more.

Access is a fundamental right for every human being. It cannot be an option or choice to cater; rather a mandate that doesn't discriminate against people based on their physical disability and instead makes use of it as a *design generator*. There are no two categories of disabled and able; it isn't the physical disability and handicap that serves as a barrier but rather the physical inadequacies of the built environment and people's prejudices that labels one as able or disabled. Thus a barrier-free environment is one that propagates for all humans to have equal independent access to the public services present.

Available Design Guidelines

1. Physical Accessibility: Harmonised Guidelines and Space Standards for Barrier-Free Built Environment for persons with Disability and Elderly Persons, 2016

2. Transport Accessibility: National Urban Transport Policy, 2014

3. ICT Accessibility: National Policy on Universal Electronic Accessibility

Since the guidelines individually addressed the creation of barrier-free environments, there was a need to harmonise all to create more comprehensive and curated documents that could be followed universally. In order to do so and make it more cohesive, a participatory approach was undertaken, which included

ministries, agencies, national institutions, state governments, and NGOs such as Samarthyam and Svayam. As a result of the steps undertaken, *Harmonised Guidelines and Space Standards for Barrier Free Built Environment for Persons with Disabilities and Elderly Persons were released in February, 2016* which are the primary guidelines referred to for the undertaken research.

Research Framework

The plethora of available design guidelines offer various design solutions and criteria that can help one to review the accessibility of spaces. Thus in order to assess the state of markets, i.e., public space for their structural accessibility the following chronology was followed to identify scales, elements and parameters of analysis. The audit checklists for accessibility are formed from observation in the urban environment and the available guidelines.

In order to develop a holistic understanding of the built environment, the mappable parameters need to take in account both *physical and sensory attributes*. Especially taking a look at spatial perception of spaces for differently abled, where certain senses are heightened in the absence of one, documentation of both these aspects can help in better identification and mitigation of the barriers in the existing environment. Taking a look at figure 1, most of the physical attributes and their space requirements are available in the form of the various guidelines listed. Further taking a look at haptic perceptions which is a sensorial attribute, is also present in the design guidelines. But the olfactory and auditory perceptions of spaces are not present.

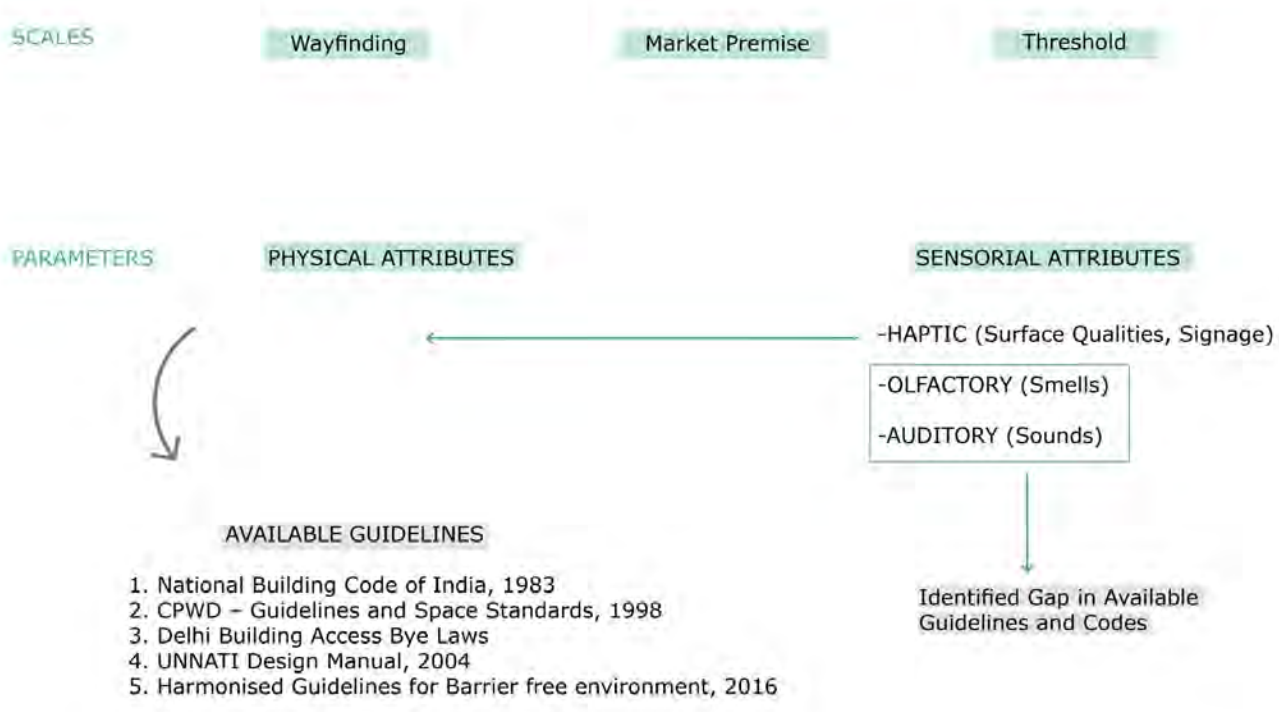


Figure 1. Attributes of Analysis

Case Studies

Markets with similar physical settings, situated in the same cultural and climatic background of New Delhi are chosen for the purpose of this study to avoid physical variables and have ease in formulation of inferences. Further, both the 'designed' markets display a similar built typology of residential and commercial. Khan Market is completely commercialised whereas Hauz Khas Market is in process of the same.

The two markets were studied were assessed for the scales of wayfinding, market premise and threshold as follows:

Wayfinding

Wayfinding relates to the route undertaken to reach from one place to another along with the user experience and orientations within it. Hence in the undertaken study the wayfinding route consists of the distance between the nearest public transport (metro station) to the market entrance.

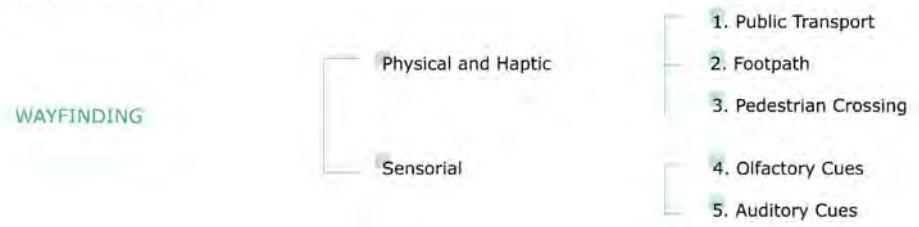


Figure 2. Wayfinding Parameters

PARAMETER	MAPPABLE ELEMENTS	AVAILABILITY
1. PUBLIC TRANSPORT (Metro Station)	1. Kerb Ramp 2. Ramp for Entry and Exit 3. Tactile Paving 4. Elevator Provision for Persons with Disabilities 5. Auditory Information and Announcements 6. Signage	Necessary elements to be present as per design guidelines
Reference:	*Agarwal, A. (2012). Public Transport: Accessible and Inclusive. Retrieved February 20, 2021, from http://urbanmobilityindia.in/Upload/Conference/669c9b20-60c0-4314-b521-ff4ed-1a671c5.pdf*	
2. FOOTPATH	1. Surface, Width and Gradient 2. Manholes and Grates 3. Vendors 4. Rest Areas 5. Kerb Ramp 6. Street Lights and Electric Poles 7. Guiding and Warning Blocks 8. Trees	Elements identified as barriers in the case studies, space requirements for the same referred through secondary sources
Reference:	*Ministry of Urban Development. (2016). Harmonised Guidelines and Space Standards for Barrier Free Built Environment for Persons with Disabilities and Elderly Persons. Retrieved January 15, 2021, from https://cpwd.gov.in/Publication/Harmonisedguidelinesdreleasedon-23rdMarch2016.pdf* *UNNATI. (2014, December). Design Manual for a Barrier-Free Built Environment. Retrieved January 15, 2021, from https://www.unnati.org/pdfs/manuals/barrier-free-built-environment.pdf*	

PARAMETER	MAPPABLE ELEMENTS	AVAILABILITY
3. PEDESTRIAN CROSSING (Only applicable in Hauz Khas Market)	A. Kerb Ramp Placement at Turnings 1. Ramp Gradient 2. Kerb Ramp Provision 3. Tactile Floor Guidance B. Traffic Signals 1. Traffic signals at each end of crossing 2. Auditory Information 3. Time interval programmed C. Zebra Crossing 1. Road bumps 2. White strips 3. Edges to the zebra crossing D. Traffic Island	Necessary elements to be present as per design guidelines
Reference :	*Shakti Foundation. (2016, April). Best Practices for Traffic Signal Operations in India. Retrieved February 20, 2021, from https://shaktifoundation.in/wp-content/uploads/2017/06/Best-Practices-for-Traffic-Signal-Operations-in-India.pdf* *Pune Municipal Corporation. (2016). Urban Street Design Guidelines. Retrieved February 20, 2021, from https://www.itdp.in/wp-content/uploads/2016/07/Urban-street-design-guidelines.pdf* *Guidelines for Planning and Implementation of Pedestrian Infrastructure. (2014, January). Retrieved February 20, 2021, from http://www.urbantransport.kar.gov.in/pedguide_final_21stJan2014.pdf*	

Figure 3. Accessibility Checklist Derivation for Wayfinding Scale

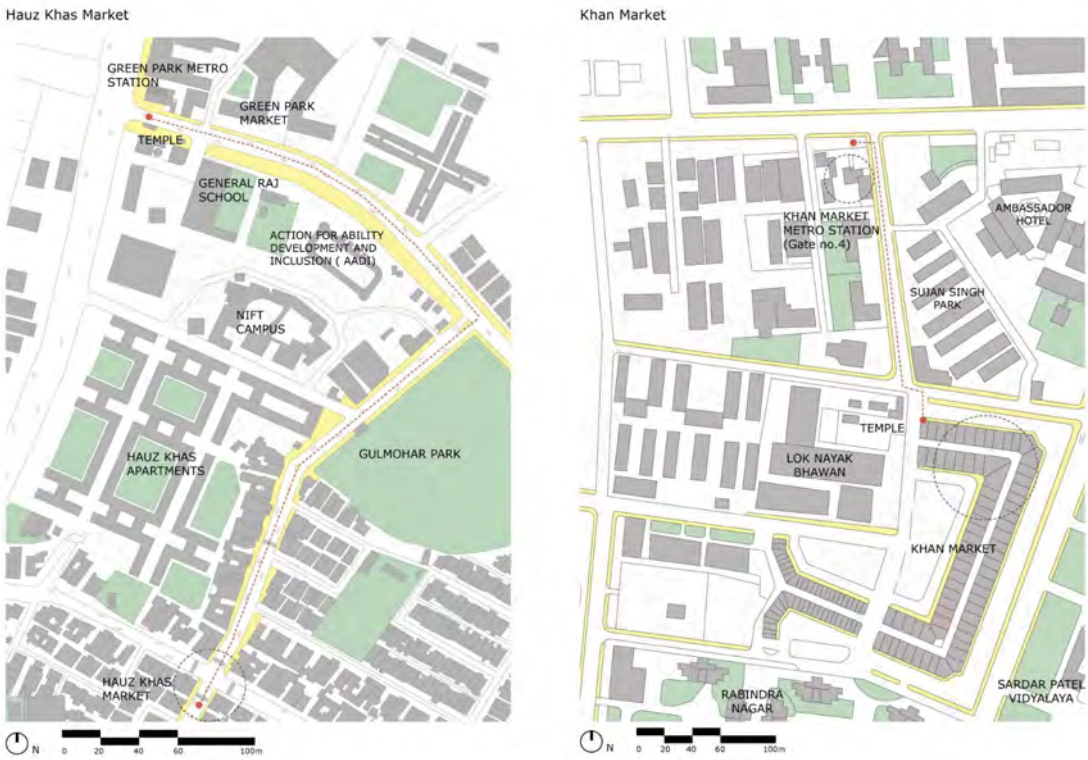


Figure 4. Wayfinding routes for Hauz Khas Market and Khan Market

Physical Attributes: Public Transport

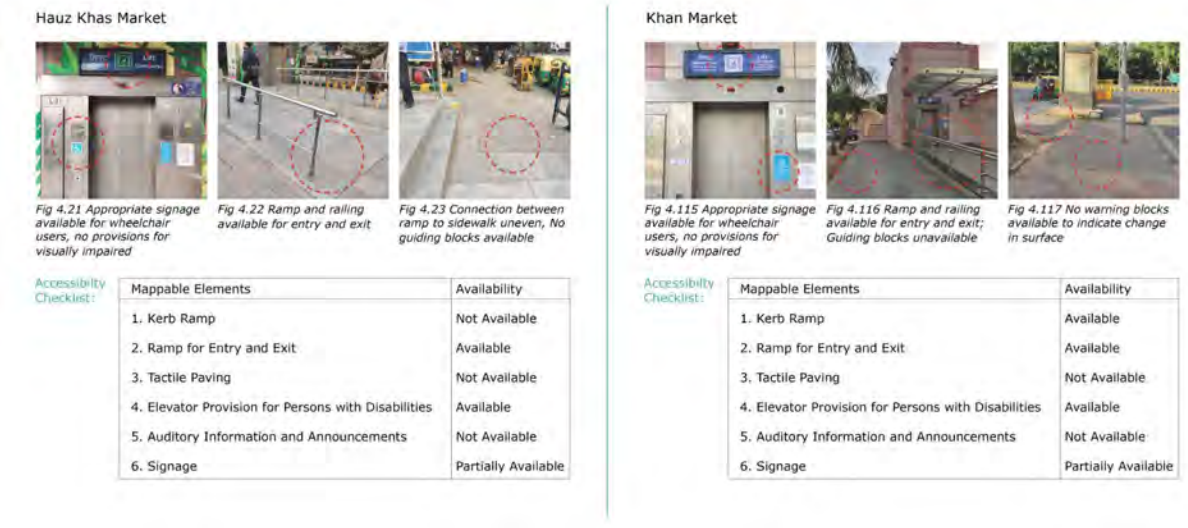


Figure 5. Public Transport Assessment

Inference: For both the markets there are no provisions made for people with vision disabilities. The only probable way they can access the station is with the help of a caretaker. Though, at the same time, adequate provisions are made for wheelchair users to independently access the station.

Physical Attributes: Footpath

Figure 6. Hauz Khas Market; Wayfinding Route; Footpath Barriers

Figure 7. Khan Market; Wayfinding Route; Footpath Barriers

Inference: Most of the interfaces between the metro station entrance to the footpath or with houses and shops on the way the footpaths are broken or there is an absence of kerb ramps.

Hauz Khas Market- There is a direct correlation between the land use of spaces and the state of the footpaths. Most of the footpaths and kerb ramps are broken or completely missing near residential areas since people make use of the spaces in front of their houses to park personal vehicles and as house entrances.

Khan Market- Wayfinding route consists of mostly shops and institutions and hence the major barriers faced are the presence of vendors and shop extensions taking up the designated footpath space.

Physical Attributes: Pedestrian Crossing

Figure 8. Hauz Khas Market; Pedestrian Crossing

It can be inferred from three physical elements (public transport, footpath and pedestrian crossing) and the nature of barriers present, that the major predicament isn't just the absence of facilities but rather the fact that most of these facilities are *broken* and *encroached*, forcing people to walk on the road instead.

Sensorial Attributes

Figure 9. Sensorial Attributes; Olfactory Cues

There are a number of *permanent smells and sounds* of traffic junctions, shops, parks that can serve as cues to navigate the built environment better. For a frequently undertaken route these smells and sounds can help create a *cognitive image map* of the route where the engaged senses can give a cue of the approaching nature of the built space.

Figure 10. Sensorial Attributes; Auditory Cues

Though the available guidelines do not acknowledge these sensorial perceptions as a mandate yet, there is a possibility that such a documentation can help in *situating an olfactory or auditory cue* vis-à-vis the existing environment such as fountains, sounds of chirping birds, etc. These cues coupled with the built environment can serve as a *directional tool* for navigation and wayfinding for the differently-abled.

Market Premise

The market premise consists of the outdoor stretch including the street and the footpath from the entrance of the market to its exit. In the cases studies documented, both markets have designed parking facilities as well, which have been considered as a parameter.

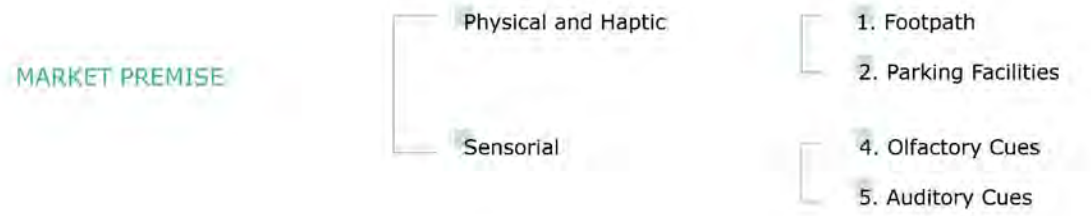
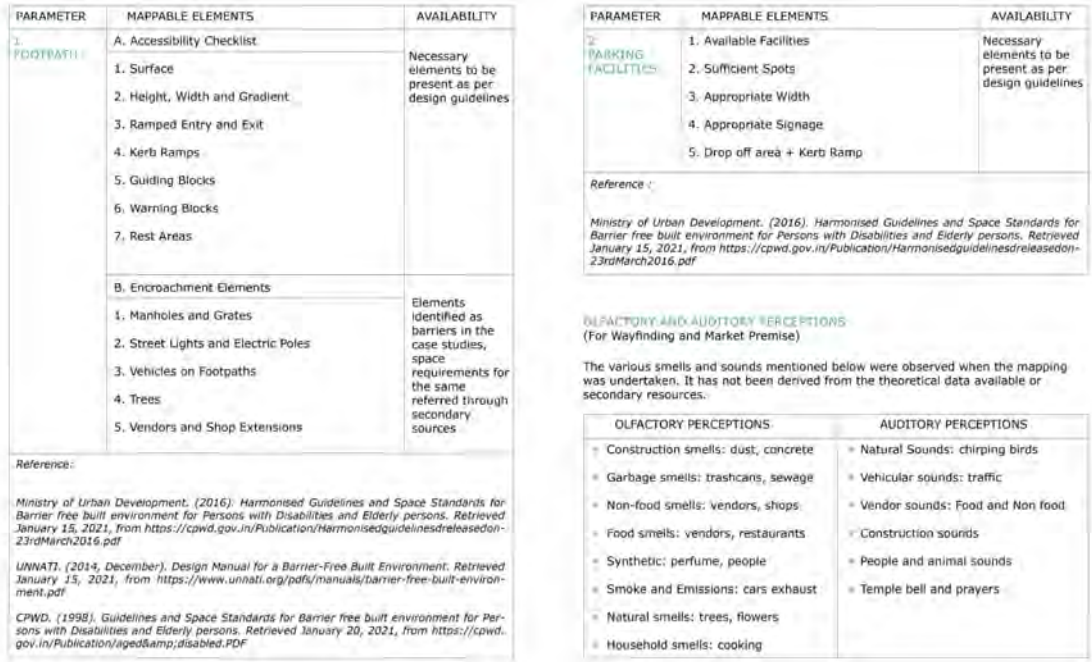


Figure 11. Market Premise Parameters



PARAMETER	MAPPABLE ELEMENTS	AVAILABILITY
1. FOOTPATH	A. Accessibility Checklist	Necessary elements to be present as per design guidelines
	1. Surface	
	2. Height, Width and Gradient	
	3. Ramped Entry and Exit	
	4. Kerb Ramps	
	5. Guiding Blocks	
	6. Warning Blocks	
	7. Rest Areas	
	B. Encroachment Elements	Elements identified as barriers in the case studies, space requirements for the same referred through secondary sources
	1. Manholes and Grates	
	2. Street Lights and Electric Poles	
	3. Vehicles on Footpaths	
	4. Trees	
	5. Vendors and Shop Extensions	

Reference:

Ministry of Urban Development. (2016). Harmonised Guidelines and Space Standards for Barrier free built environment for Persons with Disabilities and Elderly persons. Retrieved January 15, 2021, from https://cpwd.gov.in/Publication/Harmonisedguidelinesdreleasedon-23rdMarch2016.pdf

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PARAMETER	MAPPABLE ELEMENTS	AVAILABILITY
2. PARKING FACILITIES	1. Available Facilities	Necessary elements to be present as per design guidelines
	2. Sufficient Spots	
	3. Appropriate Width	
	4. Appropriate Signage	
	5. Drop off area + Kerb Ramp	

Reference :

Ministry of Urban Development. (2016). Harmonised Guidelines and Space Standards for Barrier free built environment for Persons with Disabilities and Elderly persons. Retrieved January 15, 2021, from https://cpwd.gov.in/Publication/Harmonisedguidelinesdreleasedon-23rdMarch2016.pdf

OLFACTORY AND AUDITORY PERCEPTIONS
(For Wayfinding and Market Premise)

The various smells and sounds mentioned below were observed when the mapping was undertaken. It has not been derived from the theoretical data available or secondary resources.

OLFACTORY PERCEPTIONS	AUDITORY PERCEPTIONS
Construction smells: dust, concrete	Natural Sounds: chirping birds
Garbage smells: trashcans, sewage	Vehicular sounds: traffic
Non-food smells: vendors, shops	Vendor sounds: Food and Non food
Food smells: vendors, restaurants	Construction sounds
Synthetic: perfume, people	People and animal sounds
Smoke and Emissions: cars exhaust	Temple bell and prayers
Natural smells: trees, flowers	
Household smells: cooking	

Figure 12. Accessibility Checklist Derivation for Market Premise Scale

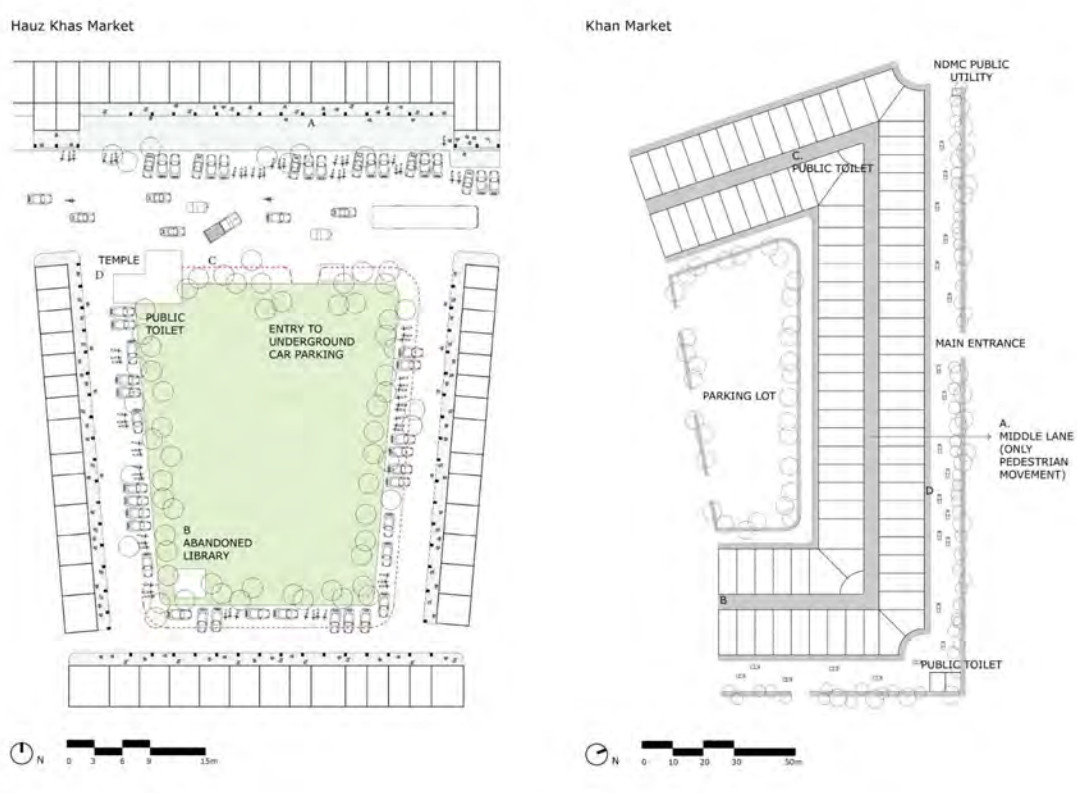

Figure 13. Market Premise for Hauz Khas Market and Khan Market

Physical Attributes: Footpath

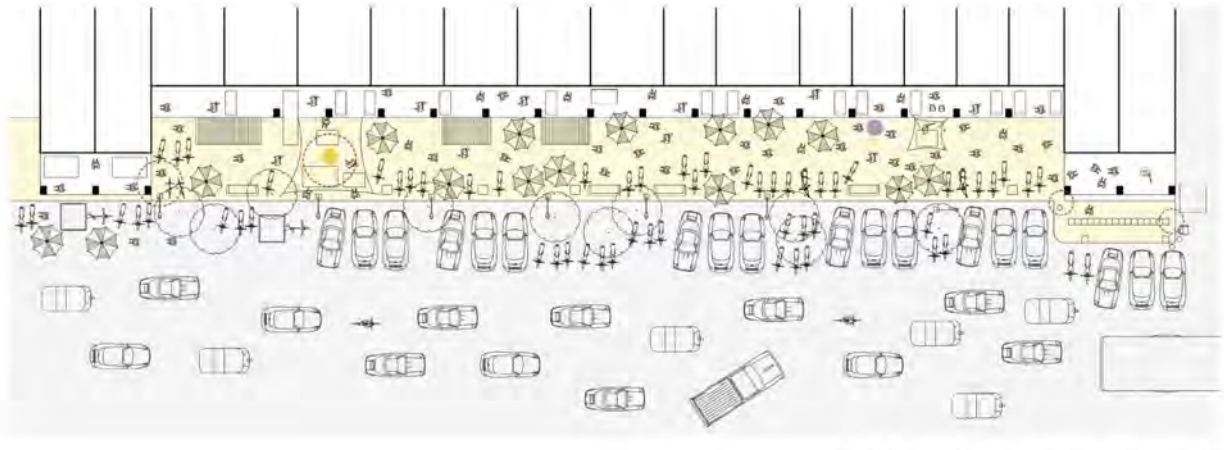

Figure 14. Barriers in Part Plan of Hauz Khas Market

The barriers in the route from the entrance to the market to the shop entrances reveal a plethora of *informal activities* which go beyond the available guidelines. For example, in Hauz Khas Market, though adequate width of footpath is available in few parts, it is heavily encroached due to vendor activities, shop extensions, vehicles parked on footpaths, manholes and grates etc.

Physical Attributes: Parking facilities

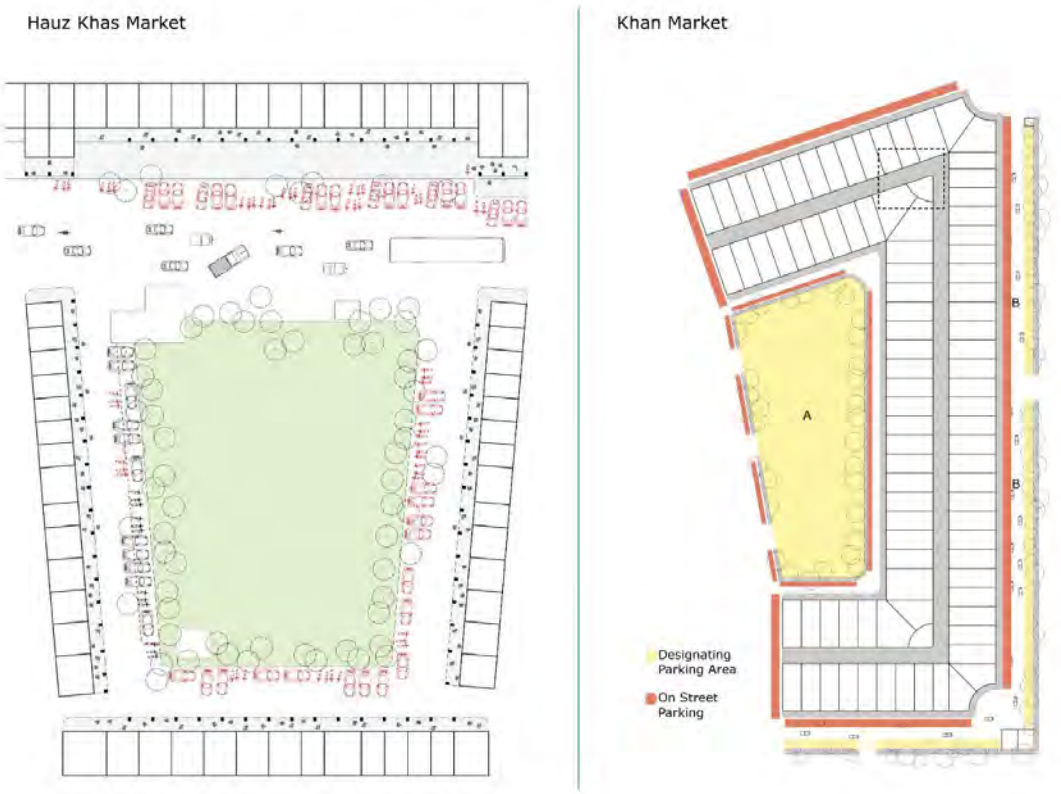

Figure 15. Parking Facilities for Hauz Khas and Khan Market

None of the markets have any spots reserved for the differently-abled. In addition to that *non-designated on street parking* due to lack of parking facilities in general, further serve as a barrier to accessibility. It takes up the street space as well as hinders movement in accessing the footpath and maintains *visibility* with the rest of the surroundings especially if one is on a wheelchair.

The role of design in the scenario is limited to and by the space requirements of the built form. Even though there is available space to accommodate for human mobility with vendors and other informal setups, together they all serve as a barrier in the built environment making it impossible for a person to move through to reach a shop.

Threshold

The threshold spaces refer to the interface between the footpath or the street to the shop entrance. These do not include the indoor environment of the various shops in the market but rather the assessment of only the entrance to the shop.

Figure 16. Threshold Parameters

Hauz Khas Market

Parameter	Mappable Element	Availability
1. Surfaces	a. Landing surface	Partially available
	b. Even surfaces	Partially available
	c. Difference in floor finish	Not available
2. Ramps	a. Entrance Ramp availability	Partially available
	b. Ramp gradient and width	Not available
3. Railings and Doors	a. Handrail/ Railing availability	Not available
	b. Clear door width and height	Partially available
	c. Independent door access	Not available

Khan Market

Parameter	Mappable Elements	Availability
1. Surfaces	a. Landing surface	Partially available
	b. Even surfaces	Partially available
	c. Difference in floor finish	Not available
2. Ramps	a. Entrance Ramp availability	Partially available
	b. Ramp gradient and width	Not available
3. Railings and Doors	a. Handrail/ Railing availability	Not available
	b. Clear door width and height	Partially available
	c. Independent door access	Not available

Figure 17. Accessibility Checklist

For the interface between the footpath and the shop entrance all the identified elements of even surfaces, railings, accessible doors and ramps are present in very few shops especially taking the example of Khan market. Being *completely commercialised* it has restaurants and shops at the upper floors as well. For all the stores in the market, hardly any of them provides for any accessible lifts or other resources that allow the differently abled to even enter the shops. It clearly illustrates that it is highly inaccessible.

Conclusion

There is no such thing as an *average user*. The plethora of barriers present in the existing environment is a clear indication that in the Indian context, public spaces are inaccessible and dissuade independent mobility for the differently abled. There is a dire need to question the commonly assumed notions of ability and disability. In the design discourse, we should critically introspect what is the after effect of viewing provision of accessible ramps, lifts and footpaths as an '*option*'.

Documentation of barriers through the lens of a particular user group i.e. differently abled allows one to see clearly the inadequacies in public spaces being equitable for all. The current public spaces as can be observed in the context of the research, creates *disparity through design*, forcing differently abled to confine themselves within the four walls of a building or a house.

Though the thesis aims to look at the documentation of barriers in the physical environment within the design discourse, there is a realisation that the urban issue of accessibility and mobility goes beyond just the reins of design. Assessing the

existing state of markets in relation to the available design guidelines indicates that there is poor implementation and maintenance despite the availability of harmonised design guidelines. *Multisensory architecture* adds meaningful layers to one's spatiotemporal experience of architecture creating a better understanding of their physical infrastructure. Mapping of the sensorial attributes reveals both aids and barriers in the given environment serving as an important wayfinding tool.

To provide an inclusive environment, *case specific documentation of barriers* and design solutions with respect to the same as mitigation strategies should be developed rather than direct implementation of the given guidelines.

Acknowledgements: *The undertaken study is an excerpt from my undergraduate research thesis at CEPT University . I am grateful to Prof. Sachin Soni for guiding the research and my alma mater CEPT University for giving me the opportunity to conduct this research.*

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Design and Implementation of Self-adapting Toilets for Semi-public Environments

Reflections on transferring a home solution to semi-public places

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Older people and persons with disabilities may face significant challenges while using a toilet. While assistive toilets at home can be tailored explicitly before or during installation to meet the individual needs and wishes, this approach fails in semi-public settings (restrooms in, e.g. restaurants, event locations or community centres). In this case, the users and their needs are not known beforehand, and thus the toilet needs to be capable of adapting itself. Based on previous successful Research and Technical Development work on prototyping an Information and Communication Technology -enhanced toilet for home use, the transfer of this concept and the necessary conceptual extensions for the out-of-home setting are outlined and reflected. Current findings show the wide variety of user needs and preferences and the different levels of technological affinity. The new toilet prototype system thus can provide different ways of physical support during toilet use and different levels of interaction, from basic to advanced, from non-complex passive use for novice users to more advanced functions for more experienced users. For example, it can retrieve previously saved settings, estimate height and detect falls based on 3D technology. A field test of the final prototype is being prepared for late 2022 to assess actual benefits.

Keywords: *toilet; adaptability; user interaction; ambient assisted living*

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Introduction and Aim

Even in Europe, the toilet situation for a significant part of the population is unsatisfactory. Astonishingly, in contrast to other areas of daily life, there has been little progress for disabled or older people in technical support for easier toilet use. However, this is a daily activity, and the problems are well known (Bichard and Hanson, 2005), (Hanson, 2007), (Kira, 1976), (Molenbroek, 2011).

Some advances beyond the simple Western-type toilet can be found in the home area: in the luxury segment with high-end electronic designs including biometric analysis and using a smart home toilet as a personal health assistant (Jaglarz, 2021), but also increasingly by basic stand-up support systems for home use and shower (bidet) devices (Jaglarz and Charytonowicz, 2015). In the area of public toilets, recently, the Changing Places (Changing, 2022) initiative for upgrading toilet rooms with changing benches and hoists for adults has emerged in the UK and very recently also in Germany (Toiletten für alle, 2022).

By default, for accessible toilets, it is mandatory to offer a fixed (raised) toilet height, which, as a compromise, does not meet the individual needs from body size, wheelchair use, and physical ability to stand up. This makes it difficult or even impossible for some people to use public toilets without personal assistance. The inappropriate height poses significant risks during autonomous use. Always having an accompanying attendant with you when leaving the house or asking other people for help in the toilet is certainly uncomfortable.

In the “iToilet” project (iToilet, 2018), we first worked on the idea of more intelligent, physically assistive toilets for disabled or older people at home. We can show the positive results from field tests with individual users whose needs, wishes and preferences are known. The semi-public (out of home) area poses additional difficulties since the usual method of customising the stand-up aid for each individual user (often before installation) is not possible. In contrast, in this area, a wide variety of unknown users must be served with excellent robustness. We set out to study a concept for such physically assistive products in the ”Toilet for me too” (T4ME2) follow-up project (T4ME2, 2022).

In other projects, we are also working on the cognitive support of people with dementia in the toilet area, another important field of research with major challenges in many areas (Ballester, 2022), (Panek, 2020). In the paper at hand, our focus is on the provision of physical support.

We also want to ensure that autonomous use without a support person being present does not compromise safety, so we included a component capable of detecting falls and emergencies and triggering automatic alarms (Lumetzberger, 2021) while respecting privacy of the user (Mucha and Kampel, 2022).

Our vision is to use modern Information and Communications Technology (ICT) in the form of innovative ICT-enhanced and safe toilet systems that adapt to the individual needs of users and enable older people and people with disabilities to participate more in societal life (Güldenpfennig, 2019), (Mayer, 2019), (Mayer and Panek, 2022), (Panek, 2017).

In this paper, we present findings from research activities and then reflect on the transfer of physically supporting toilet systems from home settings (project iToilet) to semi-public locations (project T4ME2) and the emerging design challenges.

Setting the Scene

Postures during toilet use

Many older but also physically disabled people report difficulties in the task of standing up from chairs (Chikai, 2021) and usual toilet seats (Hanson, 2007) (Kira, 1976). Therefore accessible ("disabled") toilets come with a higher toilet seat as a compromise, allowing easier stand-up for many people. This raised height during sitting on the other side weakens the stability of people with reduced strength as the feet (especially of people with shorter limbs) may not be flat on the floor to support the weight for stable sitting. At the same time on the other side, a too high position during toilet use can cause difficulties in defecation because of well-known biological principles (Sikirov, 2003). For sitting down, it also might be experienced as safer and more comfortable when the seat is in a relatively high position not requiring a large distance until the sitting position is reached.

The ideal toilet height thus differs for the different use phases (sit down, sitting, stand-up) and for different people, for most a low position is good for defecation and stable sitting but a higher position is helpful for easier stand-up.

Toilet stand-up supports and lift devices

On the market, we find several commercial devices for home use. For moving the toilet seat into the required position two methods are in use:

- A "chair" type construction, which can be simply put over an existing toilet bowl as an add-on. Here only the seat moves, not the bowl (see Figure 1).
- A wall-mounted construction, which replaces conventional toilet bowls and lifts the bowl (see Figure 2).

Some devices can only adjust the height (no inclination or "tilt"), seat always horizontal, "vertical" type), most chair type devices provide a combined height and tilt adjustment (fixed relation, especially "chair" type devices, "diagonal" type), only a few devices support the fully independent choice of height and tilt (Santis, A.S.T.).

Control of the height and tilt changes is generally provided in the form of physical buttons which offer simple manual "higher" and "lower" operations within the mechanical limits. Some devices can also be ordered with special remote control, e.g. for operation by foot.

Figure 1. Typical "chair type" devices: Santis R2D2, Economic Holland Aerolet, Solo toilet lift

Figure 2. Typical wall-mounted lift devices: Pressalit WC Lifter, Santis Silvercare, A.S.T. Lift WC

Research results on situation and needs

Users were involved via the user organisations participating in the projects, a mixed method approach was used for the study design (Mayer and Panek, 2017), (Pilissy, 2017), (Verburgt, 2021) combining qualitative and quantitative methods (e.g. interviews, questionnaires, online polls, focus groups). Main research questions were to explore the most important difficulties users do face when having to use existing toilets, the most wished / needed functionalities for better suitable toilets and the satisfaction with the tested innovative prototype systems.

Feedback collected during the iToilet project (involving visitors of an MS day care centre and patients of a rehabilitation clinic) confirmed that people are having many problems using standard and even barrier-free toilets when on their own (Figure 3).

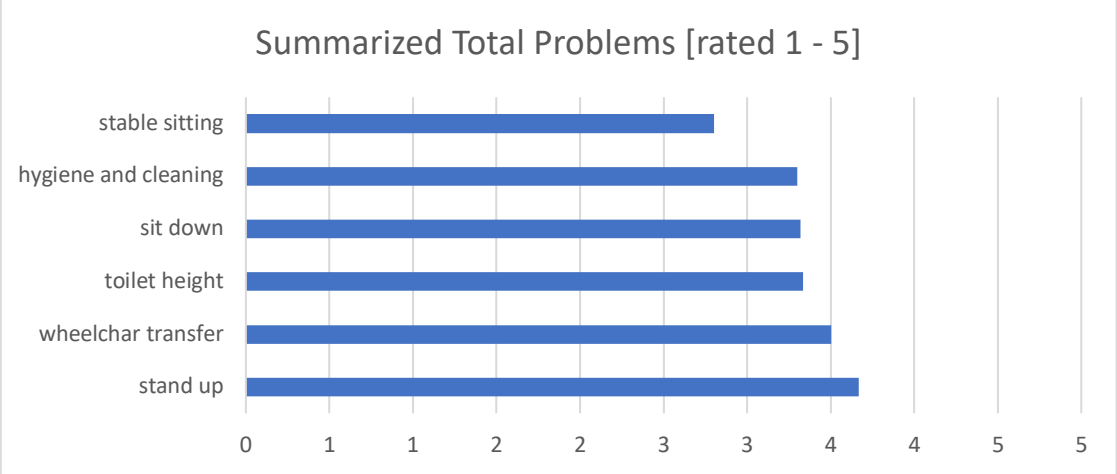

Figure 3. Summarised average ratings (1=low to 5=high) on toilet problems by all 74 primary, secondary and tertiary users (patients of a rehabilitation clinic in Hungary and visitors of an MS day care centre in Austria (Pilissy, 2017)

These users finally tested an iToilet prototype and confirmed the usefulness (Figure 4) of the individual physical support (Fazekas, 2019).

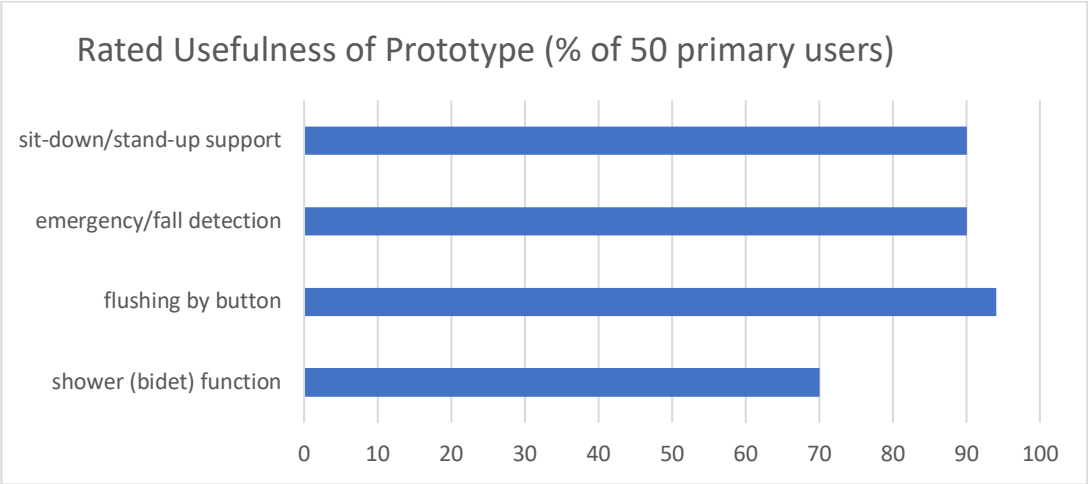

Figure 4. Total usefulness ratings for main selected functions by 50 primary users of the final iToilet prototype in Hungary (rehabilitation clinic) and Austria (MS day care centre). Opinions on bidet function in Austria were mixed while highly appreciated in Hungary.

In the current T4ME2 project, primary and secondary users in several European countries were asked to rate the many difficulties they are facing with the existing toilet infrastructure when outside the home, leading to a high amount of people stating that the lack of appropriate toilets keeps them from visiting public spaces and thus limiting them in their social activities (Figure 5).

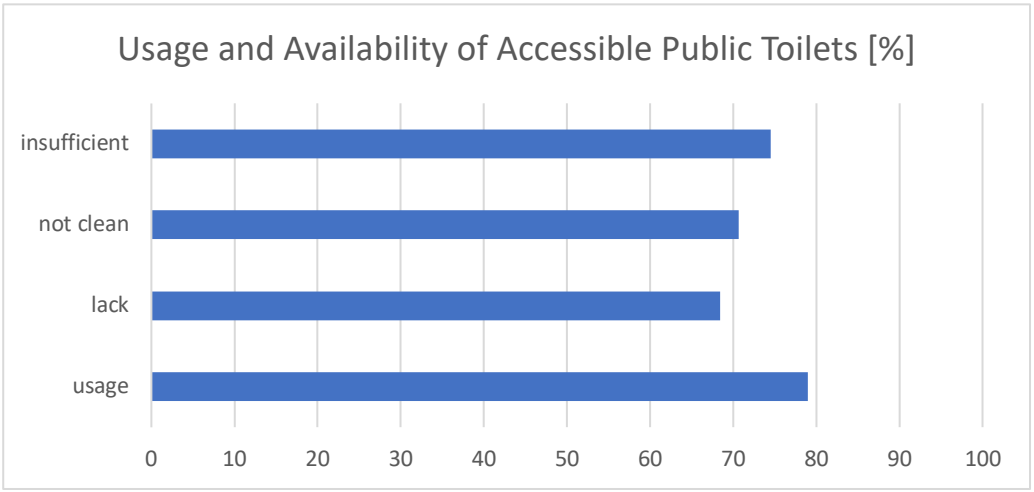

Figure 5. The percentage of usage and suitedness of accessible public toilets from 154 answers in an online poll in Austria, Belgium and the Netherlands (T4ME2, 2022), (Verburgt, 2021)

Detailed in-depth interviews then were performed with 61 primary users to learn more about their needs and opinions on semi-public toilets and the usefulness of functions (Figure 6).

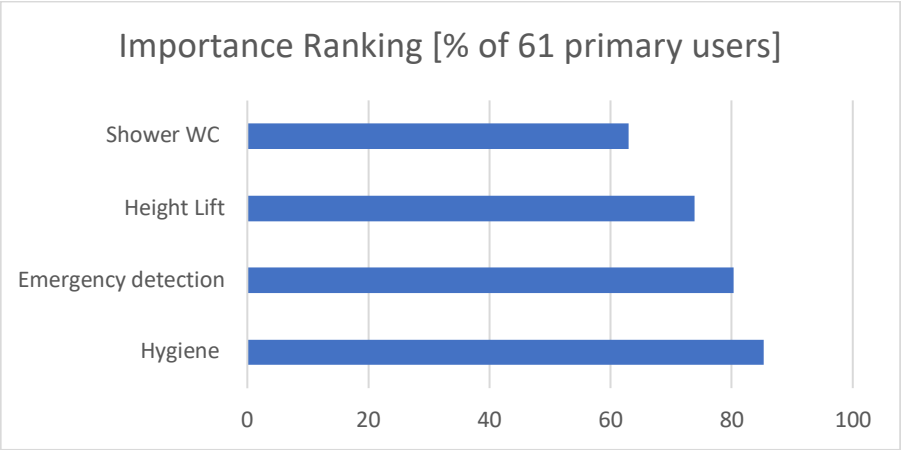

Figure 6. Importance ranking of functions from 61 interviews with primary users (Verburgt, 2021)

Many comments were also received on missing items in most toilet rooms, like adjustable mirrors, wash basins and wastebaskets, showing how little the usual barrier-free toilets fit the needs.

Reflection on Key Aspects

Smart adaptability

The variety of users in the semi-public area with their individual requirements calls for provisions in adapting the system to the preferences and needs of the users as much as possible for each current user instead of just one before installation.

Thus, the system should comprise means to get information about the users, their behaviour, and to estimate their needs. Communication between the system components should allow adding further optional features in a modular way making the system open for future enhancements also by third parties.

A flexible concept should also allow composing different solutions to fit market needs, especially also cost-related aspects.

Tests with a functional prototype

With the T4ME2 prototype 1 (PT1) we set out to demonstrate to users the different possibilities under supervision by researchers. With this we also wanted to react to the widespread lack of awareness about already existing technology. This prototype was a mobile chair-like construction (similar to those in Figure 1) to ease setup and testing which nevertheless provided new functional abilities, especially independent height and tilt adjustment, but still lacked a nice design (like cover). A smart 3D sensor (Lumetzberger, 2021) for detecting presence, position and body size of users allows to detect falls and general emergency situations like extended presence and completes the T4ME2 physical support by safety measures. The PT1 prototype represented all basically envisaged features.

Complexity and feeling of control and trust

Providing many ways of adaptation also brings the need to offer appropriate means of control. The classic way to add a dedicated button for every function quickly

leads to unmanageable complexity of the user interface for many users, especially older users who are unfamiliar with modern technological concepts, discouraging them from touching the controls. Some users prefer a “one button per function” fully manual interface over too much automatism, on the other hand, automated reactions of the system relieve the user from complexity and provide more comfort.

At the beginning of the PT1 tests, many users expressed concerns about unintentionally pressing buttons because they initially were scared by the technical appearance of the unfamiliar technology. Many users expressed fear of losing control because they doubted to be fast enough to stop unwanted movement when needed and therefore being moved to positions where they might lose contact of their feet with the floor, causing instability. But on the other hand, we also received suggestions that sensors could care automatically for individually appropriate positions. Later all users learned to control positions of the toilet quite well.

To feel safe during the use of the support system, the user has to develop trust in the underlying algorithms and experience and understand sufficiently the behaviour and reactions of the system. This definitely is a challenge given the wide range of user requirements which requires compromises.

As a major consequence in order not to scare some (mostly first-time) users, it was decided to avoid any direct user noticeable automation and complexity and use smart algorithms only in the background e.g. for pre-setting the stand-up and sitting positions which then can be intentionally activated with simple and clear commands – by those users who already got familiar with how to use it.

The PT1 test also underlined the benefit of physical prototypes for research towards new features not yet available in the market with users having hands-on experience, instead of only asking theoretical questions.

Designing functional complexity and intentional feature unlocking

During a co-design exercise with users, the design and number of buttons for the remote control were worked out (Figure 7), resulting in a layout with 8 buttons in total.

There are separate buttons for changing height and tilt. The users concluded that this would be the best compromise between too many buttons and missing options. Every button press is confirmed by the LED on top lighting up and a beep if the command is accepted by the system.

It was decided that the default state of the system should be passive like normal accessible toilets. In this state, only the FLUSH and SOS functions should be available meaning no accidental activation of movement can occur.

To unlock the movement and shower functions, an intentional signal by the user is required showing that s/he wants to make use of and is aware of the functions.

As there are no dedicated buttons for this, the activation option on the hand control is implemented as a long press on the STOP button. A beep signal confirms the activation, and then the user manually may make use of all functionality.

Additional activation options are available when the user presents preferences to the system, either by using an RFID tag or a smartphone app. The activation can comprise just the unlocking, similar to using the long press of the STOP button or also communicate preferences for the positions for the sit-down, stand-up and sitting by pre-stored values.

In the case of values given by the user for the main use positions, the movement buttons for the height also offer to go to the sitting and stand-up positions with just a

short button click instead of having to press the button until the required position is reached (similar to windows in cars).

Figure 7. Prototype of the hand control (left) based on findings from co-design activities carried out in 3 European countries (middle and right)

Another option provided by the 3D sensor of the system (which detects falls and emergencies) is to have the system estimate from a user's body size (and wheelchair use) the best positions without the need to use a tag or smartphone. After activation by the long press of the STOP button, the short click to go to the estimated positions is also available.

Of course, in any activation state, the STOP button always will stop any movement, and the usual manual adjustment of positions is always possible.

After a user has left, the system always returns to the passive state and the default position. Hence, every newly entering user finds the toilet in the usual position like every regular accessible toilet.

Hygiene and cleaning

From all research results, we see that users and stakeholders would strongly welcome solutions to keep the toilet – especially the seat - clean and technologies to support cleaning services. Possible solutions to keep toilets as clean as possible for all users range from the use of special coatings or seat material, also with antibacterial effect, to self-cleaning seats or disinfection by sprays or UV-C light after every user.

For our system concept, we decided to foresee a combination of special coating, UV-C disinfection (Jaglarz, 2020), monitoring of air quality (Orza, 2021) and estimation of usage frequency.

Many users also prefer to use a bidet shower function for their personal hygiene after use of the toilet over toilet paper because they find it difficult to reach back for cleaning or to fetch the toilet paper, others do not like it. For reasons of costs we decided to implement a shower seat.

Ethics

Our work is based on the strong involvement of often vulnerable users (Mayer and Panek, 2017) in the taboo area of going to the toilet, which makes strict compliance with ethical guidelines (Dantas, 2020), (Höllebrand and Oppenauer, 2020) and the establishment of a correspondingly well-founded interdisciplinary work (Zagler,

2008) indispensable. In the T4ME2 project, we established an ethics working group and advisory panel. In the iToilet project, we actively used tools such as the MEESTAR instrument (Manzeschke, 2015), which has proven to be very beneficial (Panek and Mayer, 2018).

Discussion of Differences between Home and Semi-public Environment

Looking at the user feedback in our projects (Fazekas, 2019), (Güldenpfennig, 2019), (Verburgt, 2021) we can conclude that the base idea of physical support is seen as helpful by a huge majority if the technology behind it is well explained. Users are even willing to use advanced functions like automatic position changes provided the user interface is straightforward, and the system is felt to be reliable.

In the example of the independent tilt function, it can be seen that unfamiliar concepts often are first not considered helpful and consequently not tried out. Once the users experience the different functions, they get interested in trying out different settings and quickly adopt strategies on how they could make the best use for themselves – but also start to imagine how useful it could be for others.

In the home environment, the so-found ideal operating principle can be easily implemented for every user. Special requirements of e.g. wheelchair users or users with low strength in the lower limbs can be taken into consideration and individual needs on the user interface can be fulfilled. Training can be individually tailored. This is similar in institutional settings.

If we go to the semi-public area we not only get an even broader potential user range but a new problem because of the to-be expected first-time users without training. The anxiety to use unknown functions and “machinery” which is looking complex here must not be underestimated, as seen during the PT1 tests.

The easy conclusion which might be drawn is to care for a nice non-technical design and limit the functions to only a few manually operated height change options like offered by simple commercial devices for home use, which is not suitable for people with different body sizes and properties. Some people not able to continuously operate manual buttons for the time needed to move the seat up could be prevented from making comfortable use, some would simply expect easy ways of moving to the main use positions fitting their needs.

This means that in one device, we would need a very simple solution for some, especially novice users, without visible complexity and scaring autonomous behaviour, and options for advanced functions without an extra complex-looking interface for more experienced users.

During business-related work with stakeholders, it became quite clear that costs also play an essential role in the adoption of smart toilets as usually only the mandatory investments into accessible semi-public toilets are taken if no clear return on investment (ROI) can be shown by offering advanced versions.

Conclusions and Outlook

The results in the iToilet and T4ME2 projects clearly show how helpful physical support by technology on the toilet can be for many disabled or older adults and that, in general, potential users and stakeholders are open to the idea, but at the same time, how demanding the task of developing such a system gets compared to

solutions for home use. The most plausible approach seems to combine modified existing components of different manufacturers together with the required new developments for smart integration.

The adaptability to the broad user range requires many different, partly contradicting functions that cannot be active altogether at any time for every user. By involving users in the test of a first prototype and co-design activities, we came up with a concept which allows providing non-complex passive use to novice users while advanced users can choose to make use of additional functionality and provide preferences.

Figure 8. The final T4ME2 prototype 2 (PT2) with some of its main components: A wall-mounted ICT-enhanced motorised lift toilet (with shower seat add-on and built-in air quality sensor), an 8-buttons hand control, RFID tags (e.g. for recalling pre-stored individual settings) and a smart and privacy-aware 3D sensor for safety and presence detection. See (T4ME2 virtual room, 2022) for a clickable online demonstration of the PT2 and the whole toilet room

In the current T4ME2 project the final prototypes (Figure 8) implementing the concepts presented above will soon be delivered to three test sites for the final real-life user trials. We expect to get rich results on how the prototypes prove in practice. From this, our business partners will develop their exploitation strategy, which could lead to better accessible toilets in the semi-public area in the future.

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Healthy and Inclusive Neighbourhoods

A theoretical framework for hearing excluded city voices

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The paper presents a 'Design for Inclusion' framework, developed for an ongoing action-research project implemented at a local level in Italy. The main goal of the research project is to define design strategies and scenarios for building healthy and inclusive neighbourhoods by co-creating two case studies with local communities of an Italian town. The design team defined a theoretical framework from an inclusion perspective, with respect to the urban furniture systems, accessories and the related services. Therefore, the paper reflects on the contribution of 'Design for Inclusion' approaches within urban health references. The result is a theoretical framework that describes how to consider 'Design for Inclusion' within a healthy and inclusive neighbourhood for designing and evaluating urban furniture systems and services. The conclusion of the paper emphasises the need for integrating 'Design for Inclusion' knowledge with social inclusion models and approaches from different perspectives such as those related to the development of inclusive services. Finally, the paper provides reflections on how the presented framework may improve the possibility to hear the diverse voices of the cities, from multiple perspectives and by using design as a strategy for creating inclusive social impacts.

Keywords: *design for inclusion; healthy neighbourhoods; inclusive cities; design for social inclusion*

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Introduction

The paper presents a Design for Inclusion framework developed for an ongoing action-research project implemented at a local level in Italy. The goal of the project is defining design strategies and scenarios for building healthy and inclusive neighbourhoods by co-creating two case studies with local communities of an Italian town. The project is co-funded by a local foundation and the local university (Department of Architecture), through a partnership between the regional health system authority, the local municipality, a local public authority consortium engaged in improving health and wellbeing, and a street furniture company. The project is going to be developed by a multidisciplinary team in the same department by involving researchers from the design (*micro-scale*), architecture (*meso-scale*) and urban (*macro-scale*) disciplines. The project started in January 2022 by developing literature review, theoretical frameworks, and desk research on three main topics i.e. inclusion, proximity, and healthy lifestyles through the built environment. Specifically, the design team defined a theoretical framework from an inclusion perspective, with respect to the urban furniture systems, accessories and the related services. Therefore, the paper reflects on the contribution of Design for Inclusion approaches such as Inclusive Design (ID), Design for All (DfA), Universal Design (UD), within urban health references and guidelines, including those that are related to age-friendly cities, active and healthy ageing, active design, healthy street strategies, social inclusion frameworks. The resulting theoretical framework describes how to consider Design for Inclusion within a healthy and inclusive neighbourhood for designing and evaluating urban furniture systems and services. The conclusion of the paper emphasises the needs for integrating ID, DfA and UD with social inclusion models and approaches from different perspectives such as those related to the development of inclusive services. Finally, the paper provides reflections on how the presented framework may improve the possibility to hear the diverse voices of the cities, from multiple perspectives and by using design as a strategy for creating inclusive social impact.

Research questions and intent

What research framework can be described in order to use the inclusion concept within a project that needs to define determinants of healthy and inclusive neighbourhoods? What kind of design approaches may contribute to it? What do we mean for *inclusion* at the *micro-scale* of the neighbourhood? By following these research questions, the scope of this work is introducing a theoretical framework for addressing healthy and inclusive neighbourhoods from the *micro-scale* perspective of the project. At the same time, we aim to understand how the Design for Inclusion approaches can contribute within urban health frameworks.

Theoretical context and the related concepts

This work mainly refers to the built environment as determinants of health (World Health Organization & UN-Habitat, 2020), urban health, and the Design for Inclusion studies.

Urban health, the built environment and inclusion concepts

In general terms, studies on urban health and the built environment mainly suggest the adoption of DfA and UD as strategies for reaching social wellbeing purposes (Mosca, et al., 2018; Capolongo et al., 2020), or for working on health vulnerabilities

by breaking physical barriers (Forsyth, Salomon and Smead, 2017). At the same time, urban planning often refers to inclusion in terms of promotion of social inclusion conditions through participation (see D'Onofrio and Trusiani, 2018) and the generation of inclusive communities, and social interactions (see London, 2020). In parallel, some studies interpreted inclusion as an objective within specific urban health perspectives such as the "*streets for life*" (Burton and Mitchell, 2006) that envisions easy and enjoyable streets in the neighbourhoods; and the "*restorative cities*" perspective (Roe and McCay, 2021), with the "*inclusive city*" concept that suggests the usage of inclusive/universal design for creating inclusive built environment. With a similar approach, the Gehl's framework of "*Inclusive Healthy Places*" (Gardner, Marpillero-Colomina and Begault, 2018) describes inclusion as (i) an outcome that accommodates peoples' diverse needs; (ii) a process that recognizes values and people of a place; (iii) a tool that can eliminate health inequities and create changes. Also, the ten principles for healthy place-making (NHS, 2019) recommend to use ID principles (Commission for Architecture and the Built Environment, 2006), Lifetime Neighbourhoods approach (Bevan and Croucher, 2011), and Healthy Streets instruments and approaches (Transport for London, 2017a; 2017b; Plowden, 2020) as resources for ensuring new places meet the needs of everyone.

Finally, UD has been proposed as a reference among the criteria for assessing the propensity of urban plans to promote Urban Health strategies (Buffoli et al., 2020). Indeed, in Italy, UD and DfA have been recognised as references for social inclusion criteria on urban health specifically related with (i) the usability of the urban space in an equitable way by different categories of users; (ii) wayfinding systems to be developed through different modes of communication (visual and sensory); (iii) participation and involvement of the diverse social stakeholders (see Ministero della Salute, 2021).

Active and healthy ageing, and inclusion

Active and healthy ageing is a challenge of the healthy and inclusive neighbourhoods project, and a topic connected with the concept of Age Friendly Cities (World Health Organization, 2007). From this perspective, 'inclusion' is seen as a diffused strategy to be adopted for the elderly needs through age friendly-environments determinants (i.e., physical environment, social environment, municipal services) (World Health Organization, 2016). In this framework, UD is considered as a key term that "*refers to the design of products, environments, programmes and services to be usable by all people*" (World Health Organization, 2016).

Indeed, the age-friendly concept refers to UD and ID standards as the main strategies for promoting participation and inclusion of elderly people through inclusive built environments and processes (see World Health Organization, 2015a) by also recognising the needs of the elderly as resources to design good neighbourhoods for everyone (Gamme and Rafoss, 2020).

Often, in considering age-friendly issues, UD, ID and DfA are recognized as similar concepts for addressing accessibility in the built environment (Chau and Jamei, 2021; Persson et al., 2015) with a problem-solving approach aimed at finding standardized solutions for all. In contrast, Handler (2018) proposes an "*alternative age-friendly"* perspective that moves away from problems solving approaches, such as:

- From instrumental approaches that solve the function of a problem, to "*Design approaches that are speculative and open-ended in their nature*";
- From approaches that try to find universal solutions that meet most of the needs regardless of age and ability, to context-specific approaches that "*that*

work to reveal, build on or amplify the social connections and networks that make up a given space";
- From object-focused approaches, to "*Design approaches that enable people to empower themselves, or lay claim to a particular space, through the design process itself*";
- From "*solution-driven*" approaches, to "*creative interventions*".

In the specific terms of active and healthy ageing, all the indicators (or factors) (World Health Organization, 2015b) relate to inclusion issues. Specifically, the physical environment is a determinant of active ageing (World Health Organization, 2002) in terms of being a facilitator to improve people's ability (World Health Organization, 2015b). The promotion of inclusive environments and the social participation of the elderly - also through UD processes (World Health Organization, 2015b) - are the two key points about inclusion within the contemporary challenge of active and healthy ageing (World Health Organization, 2020) that, in contribution with attractiveness of the outdoor and street spaces can significantly contribute to an active life of people (Cairncross, 2016).

As related with the concept of active and healthy life, the Active Design Guidelines (Lee, 2012; The City of New York, 2010) - "*as evidence-based and best practice strategies for increasing physical activity in the design and construction of neighborhoods, streets and buildings*" (Lee, 2012) - propose to create a synergy between active, sustainable and universal design. Traditionally, the US and the UK perspectives on Design for Inclusion differs from the adoption of UD and ID respectively. Indeed, the Active Design approach proposed in the UK from Sport England (Sport England, 2015) about inclusion, refers to ID. Specifically, the first principle of the Active Design approach is "*Activity for all*" by the means of "*Neighbourhoods, facilities and open spaces should be accessible to all users and should support sport and physical activity across all ages*" (Sport England, 2015). Specifically, they refer to the adoption of the ID principles defined by Commission for Architecture and the Built Environment (2006).

Social inclusion frameworks

From a wide perspective, the inclusion concept - in terms of social inclusion/exclusion - needs to be addressed as a dynamic and multidimensional concept where social, cultural, economic, political factors affect inclusion/exclusions (Levitas, et al., 2007; Popay, et al., 2008; United Nations; 2016; Taket, et al., 2014a). These dimensions have also been discussed by how they may fit on design domains and approaches related to inclusion (see Busciantella-Ricci, Rinaldi and Tosi 2019; Lim, Giacomin and Nickpour, 2021; Nickpour, Jordan and Dong, 2012; Taket, et al., 2014a). Traditionally, studies on ID, UD and DfA gave more attention to the physical and cognitive interaction of the people with their physical environment. It means aiming at reaching multidimensional inclusion through inclusive interventions made through the physical environment. Indeed, references related to social inclusion and exclusion recognised UD as a strategy to promote a socially inclusive environment (Taket, et al., 2014a; Taket et al., 2009). At the same time, the conceptual model of social inclusion as developed by the Social Exclusion Knowledge Network (SEKN) (Popay et al., 2008), identifies four dimensions (i.e. economic, political, social, and cultural) of the power relationships that constitute the continuum from inclusion to exclusion. It is a fundamental starting point for interpreting a dynamic and multidimensional approach about inclusion that works at all levels of our research project - including the *micro-scale* level. From a practical perspective, it is also possible to frame five different sections of social inclusion practices (revised from Taket et al., 2014b) that focus on policy (socially inclusive policies), service design (including universal designed environments), service delivery (attitudes and knowledge about inclusion), community life (including

participatory governance and neighbourhood renewal), and research (socially inclusive research).

Traditional Design for Inclusion approaches

From a design perspective, traditional design approaches related with inclusion - ID (Clarkson and Coleman, 2015), DfA (European Institute for Design and Disability, 2004; Bendixen and Benktzon, 2015), and UD (Ostroff, 2011) - can be framed under the common definition of Design for Inclusion (Reed and Monk, 2006; Di Bucchianico, 2021) approaches. Essentially, common values on designing accessible physical and digital contexts for all is what unites these approaches (see Persson et al., 2015), even if they differ a little in terms of design principles, methodologies and tools to be adopted for applying Design for Inclusion visions. However, for the purposes of this paper, they can contribute with specific characteristics, such as:

- about ID, the five design principles (Commission for Architecture and the Built Environment, 2006), and the design processes, tools and methodologies (Clarkson et al., 2007; Waller et al., 2015);
- about UD, the seven design principles (Story, 2011) also revised as eight goals of UD (Steinfeld and Maisel, 2012);
- about DfA, the design philosophy related to socio-political and socio-cultural drivers, and the enhancement of diversity as a value (cf. Bendixen and Benktzon, 2015; Bandini Buti, 2018), and the recent standard EN 17161:2019[1] (European Committee for Standardization, 2019).

Emergent perspectives on design and inclusion

Also, with reference to the relationship between design and inclusion emergent studies and reflections were introduced such as:

- "*Psychosocially inclusive design*" as the "*provision via design interventions of equal or equitable opportunities for a better quality of life for as many people as possible, considering both psychological and social factors*" (Lim, Giacomin and Nickpour, 2021);
- *Inclusive Service Design* approach that merges ID, ergonomics and service design (Aceves-Gonzalez, 2014; Aceves-Gonzalez, Cook, May, 2016);
- *Design for Service Inclusion* paradigm (Fisk et al., 2018);
- *Evolving Inclusive Design* framework, from the ID 1.0 (1994 - user capabilities), 2.0 (2004 - interfaces, interactions, processes), ID 3.0 (2014 - services and user diversity), ID 4.0 (2024 - systems and personalization features) (Loughborough University, no date).

Proximity and inclusion

Proximity as one of the main topics of the project, has been interpreted according to the Boschma's (2005) dimensions. Also, it has been discussed by Manzini (2022) by creating connections between proximity and social innovation as a starting point for the city that cares. This recalls the Design for Social Innovation (Manzini, 2015; Manzini, 2014) as a reference that allows to connect proximity and inclusion. Specifically, inclusion in Design for Social Innovation is mostly related to participation, co-design and empowerment of the people for social changes that

[1] It enables an organisation to design, develop and provide products, goods and services with a DfA approach; also see BS 7000-6:2005 (British Standards Institution, 2005), and ISO 9241-210:2019 (International Organization for Standardization, 2019).

often start from a context-specific process. In other words, Design for Social Innovation values present similarities with the Design for Inclusion values, especially if interpreted with a concept that can be recognised as Design for Social Inclusion (see Lee and Cassim, 2009; Ornelas and Gregory, 2009).

In summary, despite UD, DfA, and ID are recognised as the main design resources for addressing physical accessibility and promoting participation and social inclusion in urban health strategies, studies on social inclusion, on active and healthy ageing, as well as emerging Design for Inclusion studies, are opening the discussion for the need of a multidimensional perspective in combining inclusion and design. Also, the integration with different perspectives of inclusion is needed for addressing the risk of limiting the Design for Inclusion interventions to only contributing with a problem-solving approach.

Methodological approach

A theoretical framework is a structure that summarises concepts and theories from literature in order to create a synthesis of the theoretical background for interpreting what will emerge from research activities (Kivunja, 2018). By following the Kivunja (2018) guidelines, we developed a theoretical framework to use the inclusion concept within the *micro-scale* level (design) in the project related with the healthy and inclusive neighbourhoods.

Therefore, starting from the literature analysis we framed how the designs for inclusion knowledge may effectively contribute to the main topics of the project. At the same time, we integrated the framework with additional and emergent perspectives for addressing the full complexity of the action research project. Consequently, we compared the inclusion concepts with the position and the meaning of the *micro-scale* of the project as interpreted through specific design references that describe *design domains* (Jones, 2014), *design contents* (Young, 2008), and *orders of design* (Buchanan, 2001).

Results, discussion and conclusions

The main result is a theoretical framework (figure 1) we built in order to interpret the inclusion concept for the *micro-scale* level on the healthy and inclusive neighbourhoods' project. Specifically, the framework is made up of three sections - i.e. (i) 'contexts' that describe the contextualization of the framework, it focuses on urban health strategies; (ii) 'tools' as design auxilium to interpret the inclusion concept within design research fields of knowledge, it focuses on Design for Inclusion instruments mainly represented by specific Design for Inclusion approaches; (iii) 'drivers' as conceptual visions based on specific theories, it focuses on social inclusion/exclusion frameworks. These three sections present some nodes that occupy a secondary level of the framework and describe some interconnections among the sections. They are (a) 'standards' we consider within the framework, (b) 'challenges' of the project we build on the framework, (iii) the involved 'design disciplines' that better describe the *micro-scale* level in design – wich also resulted from the comparison with *design domains* (Jones, 2014), *design contents* (Young, 2008), and *orders of design* (Buchanan, 2001).

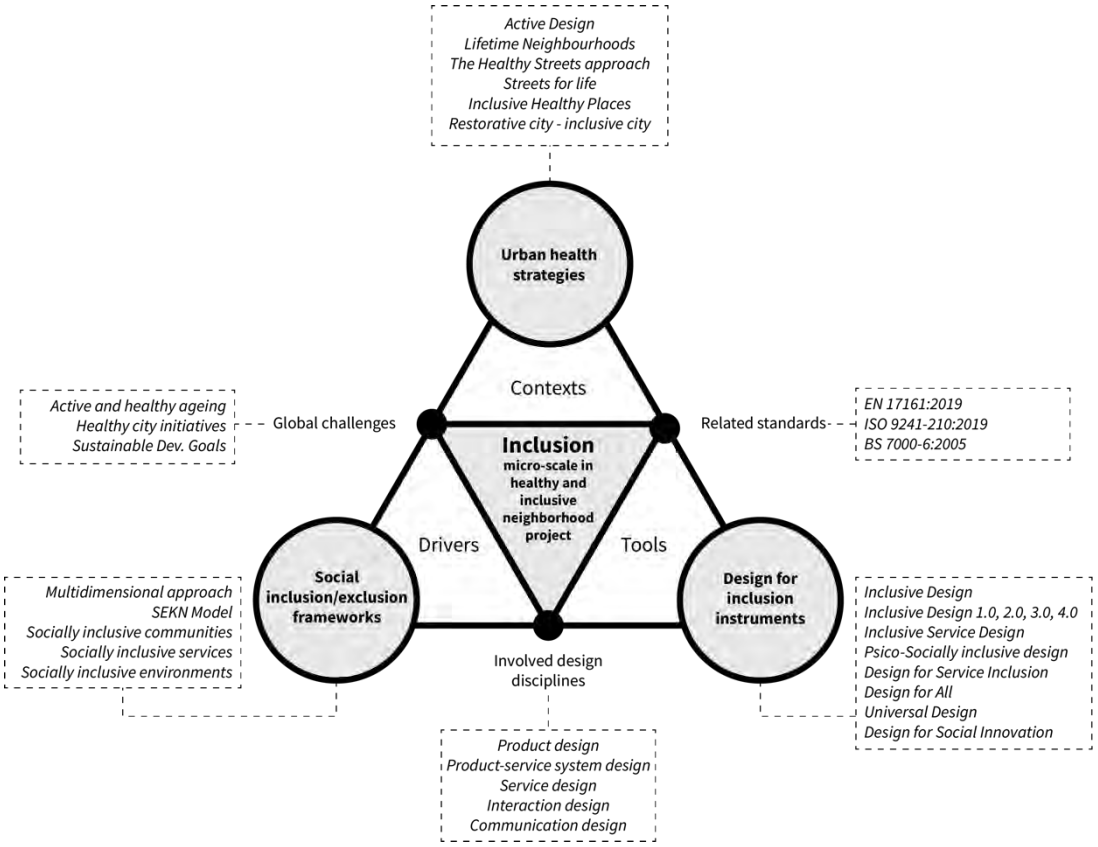

Figure 1. The theoretical framework about inclusion for the micro-scale of the healthy and inclusive neighbourhoods' project

This framework will guide the exploration and inclusion of the excluded city voices by integrating the concepts we discussed in the framework in our action research activities. Specifically, over the traditional Design for Inclusion approaches, we will focus on specific integration in order to address the complexity required in the multiscale approach, and the lack of specific design models for addressing the main topics related with the healthy and inclusive neighbourhoods' project. The framework will specifically contribute on the following aspects both useful for the objectives of the project, and as generalizable elements in Design for Inclusion researches, it will:

- introduce a more holistic approach on addressing the inclusion concept from a design perspective within a multiscale and complex project related to urban health and social inclusion;
- integrate innovative approaches and concepts within a unique framework related to design disciplines that also address intangible aspects such as service design;
- allows to consider alternative possibilities to the problem-solving approach with propositional, relational, enabling, experimental approaches (cf. Persson et al., 2015);
- be used as a tool to systematically check how the different scales of the project contribute to each other around the inclusion issues.

In general terms, this framework highlights the need of the Design for Inclusion to integrate, on one hand a multidimensional approach through social inclusions frameworks, and on the other hand considering and advancing emerging approaches, ideas, and concepts such as the Inclusive Service Design, the ID 3.0 and 4.0, the Design for Service Inclusion. This integration can be particularly

relevant in multiscale projects because the built environment of the *micro-scale* level can be a touchpoint of complex intangible systems such as a service or a community, and these new approaches may help in creating a systematic framework for addressing these issues.

In addition, this work presents some limitations. Firstly, the framework is not the full interpretation of the inclusion concept within the healthy and inclusive neighbourhoods' project. The evolution of this framework in collaboration with the other scales of the project is one of the next steps related to this paper. Also, the framework has been only validated within the internal design team (*macro-scale*) of the project. A validation with the stakeholders' group is needed. Finally, this work presents an early version of the framework that needs iteration processes as well as a validation on the field during co-design activities with key actors of the project. We do not exclude that the framework can assume significant changes due to in-field activities we will provide.

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Inclusive and Sustainable Fashion Product-Service System for Evolving Bodies during / after Pregnancy

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Media and fashion systems have shaped ideal and stereotyped female bodies, imposing an unattainable aesthetic image based on extreme slenderness, perfection, and tone, thus causing social anxieties, and unhealthy self-relationships. In 2019, Mental Health Foundation showed that 66% of UK women were affected by body dissatisfaction due to their bodies' changes during maternity.

This paper investigates mothers' relation with their body image during/after pregnancy through a user-centred design approach. We surveyed 97 mothers and interviewed 2 perinatal psychologists and 2 body experts to understand methods of confidence-building during pregnancy and experience with maternity clothes. Based on the received feedback, we designed and empirically tested Nawale, an inclusive fitting garment adaptable to female bodies during/after pregnancy via (i) flexible auxetic textile patterns, (ii) lacing, and (iii) interlocking systems (connectors) from laser-cutting technologies. Users can co-design the garments customising on body shapes and preferences at the online virtual fashion platform. It allows users to preview the custom garments in a virtual fitting room and set a networked on-demand production.

The resulting project aims at (i) tackling body image change and dissatisfaction of pregnant women, (ii) boosting self-confidence, and (iii) increasing diversity in fashion, toward inclusivity, and social/environmental sustainability.

Keywords: *fashion design; social sustainability; auxetic textile; product service system design; inclusive design*

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Introduction

Body image and dissatisfaction during/after pregnancy

Body dissatisfaction is a person's negative thoughts and feelings about his or her body (Grogan, 2016). It refers to the perceptions people have of their physical appearance and the emotions caused by these perceptions. The media and society promote the idealisation of slenderness and beauty portraiture and stipulate that everything that manages to look like those beauty standards is good (Grogan, 2016). Thinspiration and fitspiration media contents contain guilt-inducing messages regarding the weight of the body, fat stigmatisation, the presence of objectifying phrases, and dieting messages (Cohen et al., 2019). These messages change women's perception of themselves by teaching them socially acceptable ways in which they should behave. Therefore, women were found to have more body dissatisfaction than men (Kostanski & Gullone, 1998), presenting dissatisfaction with their bodies due to an idealised beauty benchmark that they wanted to achieve (Charles and Kerr, 1986). Specialists have found that since the age of eight years old women feel insecure about their bodies and that this feeling lasts throughout all their life (Grogan, 2016).

Pregnancy and postpartum represent a critical risk period for developing and exacerbating anxieties caused by body dissatisfaction (Johnson, et al., 2004). During pregnancy, women are vulnerable to mood and anxiety disorders due to the significant physical and emotional changes that occur during this period. Pregnancy-related anxiety is associated with the fears and worries centred around pregnancy (Bayrampour, et al., 2016). Women feel concerned about the process and health of the unborn baby. Within this disorder, women can experience poor psychological adjustment and self-care, low self-esteem, increased weight gain and nausea, and negative views of motherhood. Even when they have a health reason to not fulfill the beauty stereotypes, they are judged and pressured to return to their previous shape as soon as possible to ensure to be a good mother (Malatzky, 2017). Earle (2003) found that women indicate three main concerns in relation to their bodies: how they would look when their pregnancy began to show, where the changes in their bodies would occur and how easy it would be to return to their old shape. Furthermore, women indicate that they feel more concerned about their bodies during the last trimester as compared to the onset of pregnancy and pre-pregnant phase, particularly in the breast and the stomach (Breda et al., 2015). Other alterations like stretch marks, acne, skin pigmentation, and varicose veins cause serious problems of confidence that are generated mainly by a strong social comparison created by the media and the friends and family nucleus (Dryer et al.,2020), along with the fashion system producing standardised sizing clothes that does not fit everybody (Grogan, 2016). Ogle et al. (2013) found that maternity clothes were considered expensive, ugly, and unattractive, causing anxiety in women because they symbolised someone that they did not want to be associated with. Since clothes are considered a way to satisfy the individual, social and physical human needs, as well as the cultural representations and art forms (Kaiser, 1997), reflecting their identity and being directly linked to the way people look and feel about their image (Tiggemann & Lacey, 2009), new clothing systems should address the needs and concerns of pregnant women becuase they could affect their personality and behaviours (Lennon et al., 2017).

Methodology of the research

Aim of the research

The research focused on creating a product-service system to promote mothers' body satisfaction and reduce anxiety during/after pregnancy, meanwhile implementing a circular fashion process to promote sustainable maternity products. The aim is to explore and design a product-service system that can eliminate the standardisation of sizes and reduce body dissatisfaction caused by clothes anxieties. In addition, its aim is also to create a more inclusive service in which users can feel integrated and where the body can be evaluated for what it can do and not so much for its appearance. The system wants to promote the creation of products that can be adjusted to the different stages of pregnancy, as well as the customization of the garment so that women are in control. To define the project/system requirements, two main research methodologies were adopted: (i) user-centred research through qualitative and quantitative mixed research strategies to understand the users' fears and needs and their experiences during pregnancy; (ii) material experimentation with research through design approach to investigate how to implement flexible, adaptable, and sustainable solutions for garment design through the application of new technologies such as laser-cutting techniques.

Materials and Methods

1) User-centred research

1 quantitative/qualitative survey (28 questions in Spanish, Italian, and English) and 2 qualitative interviews were developed and administered online. The survey was delivered to 97 women (11% pregnant women, 86% mothers at the time of the survey; average age 35 years old; Nationality: 80% from Mexico, 15% from Italy, 1% from Brazil, 2% from Venezuela, 1% Colombia, and 1% Norway) to collect experiences about: (i) body image during and after pregnancy, and (ii) women's relationship with maternity products (clothes and accessories) on the current market. The semi-structured interviews were directed to 2 perinatal psychologists and 2 body experts (a nurse and yoga instructor and a massage therapist, experienced in working with pregnant women) about (iii) methods to build confidence. Data were collected and treated with the consent of the participants and elaborated by aggregating and anonymizing the results.

2) Material experimentation

The empirical testing of laser-cutting technologies on fabrics materials was useful to iteratively design and test flexible, adaptable, and sustainable garments based on the zero-waste pattern-making logic to offer a custom, inclusive, circular service that could be accessible worldwide. The experimentation focused on three different adaptable solutions (e.g., auxetic structures, interlocking systems - connectors and lacing) and was developed on Rasone (100% polyester woven fabric weigh 0.0186 gr/cm2), Mollettoni (65% polyester + 35% viscose non-woven fabric weight 0.0329 gr/cm2, and Cotton Neoprene (92% polyester + 8% spandex knit fabric weight 0.0385 gr/cm2).

Auxetic structures can expand and shrink in all directions when stretched and compressed, thus adapting to the precise shape of the user's body (Papadopoulou, et al., 2017), creating comfortable and adaptable clothes for different maternity stages (Hu, et al., 2019). For the research, 11 different auxetic structures were

laser-cut into 10x10 cm synthetic fabrics swatches to test their behaviour in terms of expandability and flexibility, aesthetic, texture, and manufacturing difficulty on a three points scale (see Table 1). Swatches were also digitally tested using CLO3D software with the intention to compare the physical and digital behaviours with the intention to make them visible on an online platform.

Table 1. Evaluation criteria for the experiments of auxetic structures

PROPERTY	VALUE		
	1	2	3
EXPANDABILITY AND FLEXIBILITY	It does not have great flexibility.	It has medium flexibility.	It has great flexibility.
AESTHETIC	It does not look good when it comes to expanding. There exists to mush deformation of the figures.	It looks nice when it expands but it presents some deformation.	It does not present a great deformation. The figures look nice and clean.
TEXTURE	It creates a scratchy and unpleasant texture to the touch.	It has a good feel texture, but it is not comfortable.	The texture created is soft and pleasant to the touch.
MANUFACTURING DIFFICULTY	It breaks, it frays, it burns. It cannot be used on laser cut machine.	It does not break; it does not fray. But it still requires special adjust-ments to be used on laser cut machine.	It does not break, it does not fray, and it does not have any complication of been produced on laser cut machine.
DIGITAL BEHAVIOR	It does not change. The visualization is not well developed. It seems to be static.	It behaves a bit like the physical sample, but it is still not 100% accuracy.	It behaves like the physical sample. It looks real.

Interlocking systems/connectors allow the creation of a modular design of parts that can be detached, modified, relocated, and replaced for upgrading, repair, recycling, or reuse (Gu, et al., 2009). This system decreases shipping pollution and impulses local production. For the research, 19 different interlocking system samples were designed, laser-cut, and tested to evaluate stretch resistance, aesthetic, manufacturing difficulty, and assembly difficulty (on a three points scale) and to select the most suitable ones to be applied on zero waste garments and accessories (see table 2).

Table 2. Evaluation criteria for the experiments of interlocking systems/connectors

PROPERTY	VALUE		
	1	2	3
STRETCH RESISTANCE	The union does not resist, it opens very easily when stretching the fabric.	The joint resists a little when stretching the fabric, but it opens with the frequency of stretching.	The union remains intact when stretching the fabric, it does not break.
AESTHETIC	They do not look good, it generates lumps.	They look good, but they generate deformations.	They look good. They help to generate design details, or they are not visible at all.
MANUFACTURING DIFFICULTY	It breaks, it frays it burns. It does not good to be used with laser cut machine.	It does not break; it does not fray. But it still requires special adjustments to be used on laser cut machine.	It does not break, it does not fray, and it does not have any complication of been produced on laser cut machine.
ASSEMBLY DIFFICULTY	It is not easy to assemble, it takes a lot of time.	It is more or less easy and quick to assemble.	It is easy and quick to assemble, it is intuitive.

Lacing is a fastening method used in clothes that allows garments adaptability to new requirements, garments' reuse when circumstances change in time (Gu, et al., 2004), and opening adjustability (Sarina, 2022) to different bodies and sizes, in particular for pregnant women (Rybarczyk, 2020). It was also used as a decorative element in western ladies' clothing of the 20th century (Rogers, 2020). In this research, lacing technique was explored through the sole use of laser-cutting techniques by developing a 10x10 cm sample of perforated holes with a constant distance of 2x2cm spacing. Likewise, digital prototypes through CLO3D were made to observe the size and the adequate distance of the perforations in different areas of the body.

Results

Physical and psychological during/after pregnancy needs

60% of the surveyed women admitted having suffered insecurity about their appearance during pregnancy and postpartum and fear of being unable to lose weight. Most of them consider pregnancy as a body *"deformation"* that results in discomfort and resignation. Despite this, they did not consider it necessary to take a specific therapy to treat body dissatisfaction during pregnancy. However, they perform physical activities such as walking to stay toned and do relaxation practices such as yoga, stretching exercises, massage, and physiotherapies during pregnancy and post-pregnancy. These practices belong to the functionality theory (Wood-Barcalow *et al.,* 2010). Women look for support groups of other mothers, in family and outside (e.g., motherhood counseling). In relation to clothes, pregnant women need maternity clothes that do not limit their movement. Current maternity clothes and accessories are considered ugly, with a not-unique and customised design, expensive and disposable: at childbirth, they are thrown away or donated.

The experts argued that body dissatisfaction in women during pregnancy is linked to the lack of knowledge and full awareness of what it means to have a baby. The experts use functionality (Alleva & Tylka, 2020) to construct psychological confidence and security and physical activity to decrease the feeling of anxiety. In addition, they use the feminism theory (Peterson *et al.,* 2006) to question gender roles and to put patients' expectations and problems into visible words. Experts consider that it is essential to design functional tools to promote the bonds of motherhood and to rebuild women's new identities during and after pregnancy to help them feel free and independent.

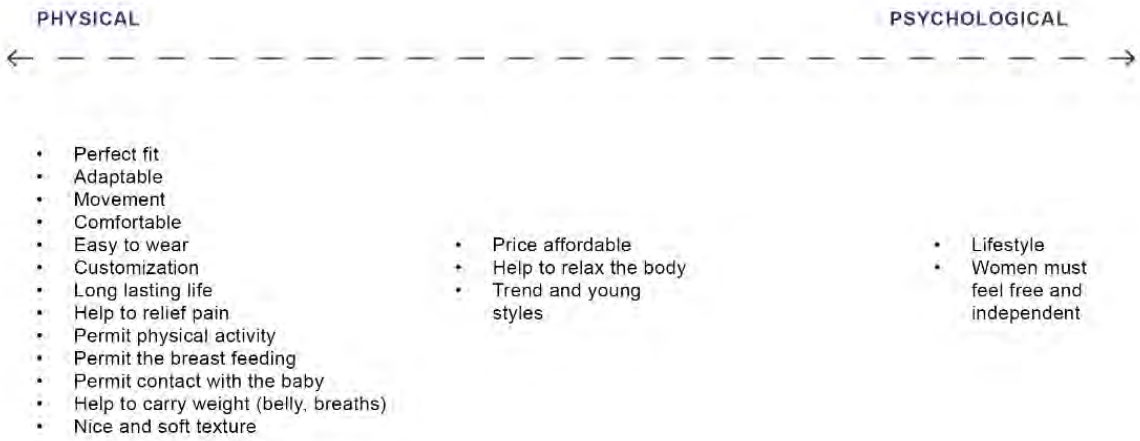


Figure 1. Physical and psychological needs emerged from the user-centred research

Connection, flexibility, and adaptability: empirical results

To respond to the emerging functionality and physical needs, a series of experiments on materials and shapes were performed thanks to the use of laser-cutting technologies to test the adaptability to movement, comfort, perfect fit, and easiness of wear during and after maternity.

In particular, 11 auxetic structures were designed and tested to check expandability, aesthetics, resistance, and difficulty/simplicity in laser-cutting (see table 3). The expandability of auxetic structures depends on the design of the cuts (bigger cuts, higher expansion) and materials (higher flexibility of the material, higher expansion). The size of the cuts is also linked to the transparency that the piece could have (larger cuts, wider openings, higher expansion, more transparency). Several samples (e.g. hexagon) scored low due to the fragility of joints derived from low cut tolerances. The digital and physical expansion of the materials was not the same due to the impossibility of the CLO3d software to simulate real behaviours. This means that physical samples are required to understand the real behaviour of the auxetic structures to be further applied to the visual representation of digital fabrics in the virtual world

Table 3. Evaluation processes of auxetic figures

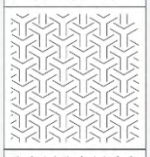
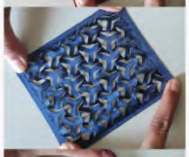
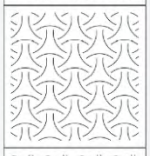
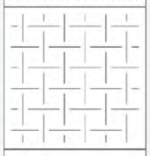
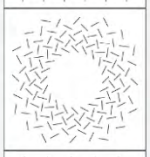
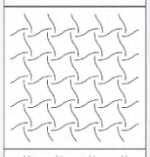
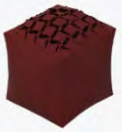
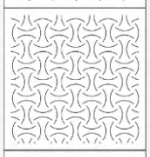
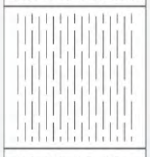
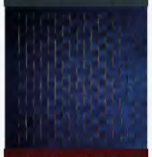
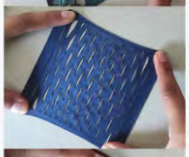
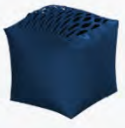
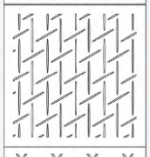
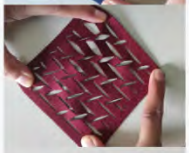
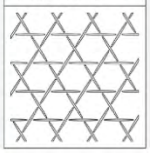
NOMENCLATURE	TECHNICAL DRAWING FOR LASERCUTTING	TEXTILE CUT	CHECK ON STRETCHABILITY	SIMULATION ON CLO3D	COMMENTS
FIGURE: 1 WAVES					Large cuts greater flexibility. Extra volume and texture are formed with the expansion
FIGURE: 2 Y					Greater number of cuts more flexibility, less tolerance to breakage
FIGURE: 3 TRIANGLE					Thick materials less flexibility
FIGURE: 4 BOWS					Greater number of cuts more flexibility, less tolerance to breakage, and rough texture
FIGURE: 5 SQUARE					Higher flexibility of the material, higher expansion
FIGURE: 6 SWIRL					Smaller cuts less flexibility and less transparency
FIGURE: 7 PINWHEEL					Thick materials less flexibility
FIGURE: 8 PINCHES					Higher flexibility of the material, higher expansion, more transparency
FIGURE: 9 LINES					Higher volume and better aesthetics on curved surfaces
FIGURE: 10 RHOMBUS					Thick materials less flexibility
FIGURE: 11 HEXAGON					Consider tolerance and distance between cuts

Table 4. Evaluation processes of interlocking systems

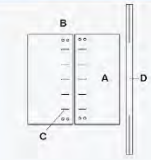
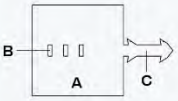
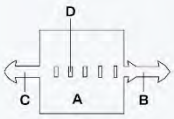
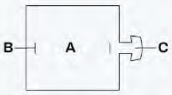
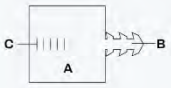
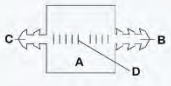
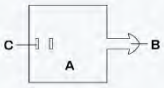
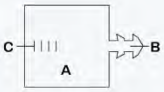
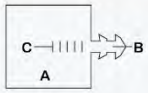
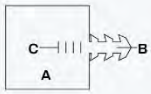
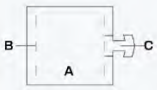
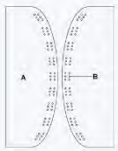
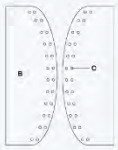
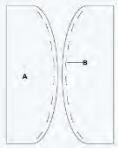
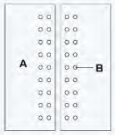
NOMENCLATURE	TECHNICAL DRAWING FOR LASERCUTTING	SIZE SAMPLE	DISASSEMBLED CONNECTOR	ASSEMBLED CONNECTOR	COMMENTS
CONNECTOR: 1		A: 6x12 cm, B: 1.5 cm r, C: 1cm, D: 0.9x20 cm			In light materials use mechanisms with strings and slots
CONNECTOR: 2		A: 5x5cm B:.2x.6cm C: 1.5x2.8cm			Considered tolerance of joints and material thickness
CONNECTOR: 3		A: 5x5cm B: 2.7x1.2cm C: 2.1x1.2cm D: .1x.6cm			Considered tolerance of joints and material thickness y structure.
CONNECTOR: 4		A: 4X20cm B: .9cm C: 2cm			The interlocking systems with the connector on one side and slot on the other are less resistant than the ones with connectors and slots on both sides
CONNECTOR: 5		A: 6X10cm B: 1cm C: .9x20cm D: .3 cm r E: 4.5x1.8cm			Connectors can be used as fasteners.
CONNECTOR: 6		A: 65.5x5cm B: .6cm C: 1.3x1.5cm			In light materials without structure the joints break. In light materials it is better to use mechanisms that seal completely (strings and slots)
CONNECTOR: 7		A: 5X5cm B: 2.5x1.6cm C: .6cm			In light materials without structure the joints break. In light materials it is better to use mechanisms that seal completely (strings and slots)
CONNECTOR: 8		A: 5x5cm B: 2.5x1.6cm C: 2x1.5cm D: .7cm			More points contact more difficult to open, although it takes longer to assemble.
CONNECTOR: 9		A: 5x5 cm B: 2x1.3cm C: .1x.6cm			Connectors made in unstructured fabrics do not resist
CONNECTOR: 10		A: 5x5cm B: 2x1.5cm C:.6cm			In light materials without structure the joints break. In light materials it is better to use mechanisms that seal completely (strings and slots)

Table 4 (continued). Evaluation processes of interlocking systems

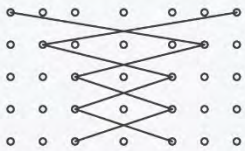
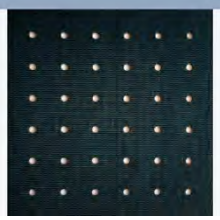
NOMENCLATURE	TECHNICAL DRAWING FOR LASERCUTTING	SIZE SAMPLE	DISASSEMBLED CONNECTOR	ASSEMBLED CONNECTOR	COMMENTS
CONNECTOR: 11		A: 5.5cm B: 2x1.5cm C: .6cm			The best fabrics in terms of aesthetics and resistance present structure and friction useful to maintain the shape and sustain a stronger locking system
CONNECTOR: 12		A: 5x5cm B: 2.5x1.5cm C: .6cm			Although the interlocking systems have many points of contact, if the fabric does not have structure and friction, the interlocking systems will break.
CONNECTOR: 13		A: 5x5cm B: .6cm C: 1.3X1.4cm			In light materials without structure the joints break. In light materials it is better to use mechanisms that seal completely (strings and slots)
CONNECTOR: 14		A: 4x20cm B: .9cm C: 2cm			The interlocking systems with the connector on one side and slot on the other are less resistant than the ones with connectors and slots on both sides
CONNECTOR: 15		A: 5.5x17.5cm B: .1 cm r			Strings and slots have good strength on lightweight fabrics (non-knitted), but they take more time to assemble them
CONNECTOR: 16		A: 6.5x17.5cm B: 15cm			Connectors work better on straight patterns than on curves. Deformations in the joints occur when there is an accumulation of material and a pronounced curve.
CONNECTOR: 17		A: 6.5x17.5cm B: 1cm			Connectors work better on straight patterns than on curves. Deformations in the joints occur when there is an accumulation of material and a pronounced curve.
CONNECTOR: 18		A: 4x10cm B: .15cm			Strings and slots good resistance. Consider knot volume
CONNECTOR: 19		A: 4X3cm B: 4.5x3cm C: 3.5x3cm			The best fabrics in terms of aesthetics and resistance present structure and friction useful to maintain the shape and sustain a stronger locking system

For the interlocking systems, we designed and tested 19 connector samples (see table 4) on three different materials to test the stretch resistance, aesthetics, functionality, ease of use, and manufacturing through laser-cutting. The stretch resistance of the connectors derives from the fabric structure and the design of the

lock. The best fabrics in terms of aesthetics and resistance present structure and friction useful to maintain the shape and sustain a stronger locking system. Furthermore, the more contact points an interlocking has, the less likely it is to break, although it takes longer to assemble. Although it was observed that the connectors composed of strings and slots were the best option for soft materials, these also took more time to assemble. During the design process, it is necessary to consider the tolerance of joints and material thickness, allowing friction and resistance but also ease of assembly. On the samples, it was evident that the interlocking system with connectors and slots on both sides worked better and had better resistance than the ones with the connector on one side and slot on the other (e.g. connector 4). Connectors work better on straight patterns than on curves (e.g. connector 17), since deformations in the joints occur when there is an accumulation of material and a pronounced curve (e.g. connectors 15, 16, 17). It is necessary to calculate the precise distance of the connectors to create a more defined round figure.

A physical sample and a digital sample of the lacing mechanism were developed (see table 5) through laser cutting circles with different distances to create a grid where a cord can cross and thus generate the adjustment of the garment. The test showed that it is possible to realise the lacing fastener by a single production process (laser cutting) and that this technique could be used in different parts of the body without causing discomfort and unwanted alterations in the silhouette. Likewise, the digital sample prototype with CLO3D showed that the circles could be personalised and adjusted to the user's measurements and silhouette.

Table 5. Evaluation lacing mechanism

MECHANISM EXAMPLE	TEXTILE CUT	SIMULATION ON CLO3D	COMMENTS
			It is possible to realize the lacing fastener by laser cutting, and it could be used in different parts of the body without causing discomfort. Circles could be personalised and adjusted to the user's measurements and silhouette.

Inclusive and sustainable fashion product-service system for evolving bodies during/after pregnancy

The previously carried out research was used to design Nawale, a product-service system that allows pregnant women to customise garments based on their style and particular body shape, changeable during different pregnancy stages. The system is composed of (i) two adaptable zero-waste dresses that could be personalised by the user thanks to a (ii) digital platform that allows sustainable on-demand production.

The two dresses include both auxetic structures on the abdominal, central back, and breast area that present more significant changes during pregnancy, and lacing mechanisms were implemented on the front and back to make the garment's adjustment easier. One of the dresses (Figure 2) could be produced on-demand using the traditional approach of product manufactured and assembled in the company workshop and sent to the clients once it's finished. The second dress (Figure 3) could be produced through networking on-demand production that relies on digital drawings sent to the user to be produced by the worldwide network of

fablab using laser-cutting and to be assembled by the user. This dress also includes interlocking systems in place of sawing on the edges of the pattern to allow the self-assembly of the piece at home by non-expert users.

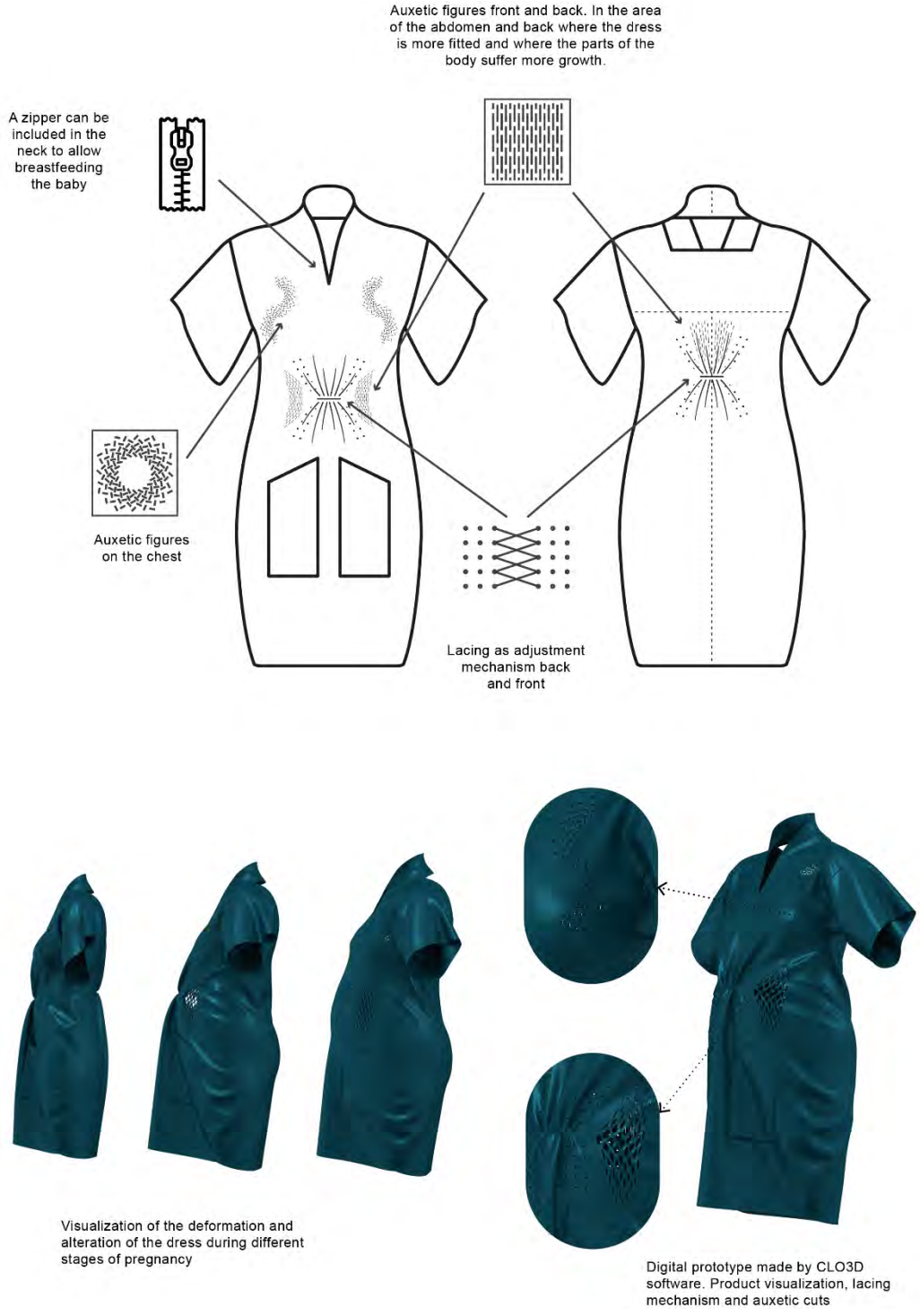


Figure 2. Dress to be produced by traditional production without connectors

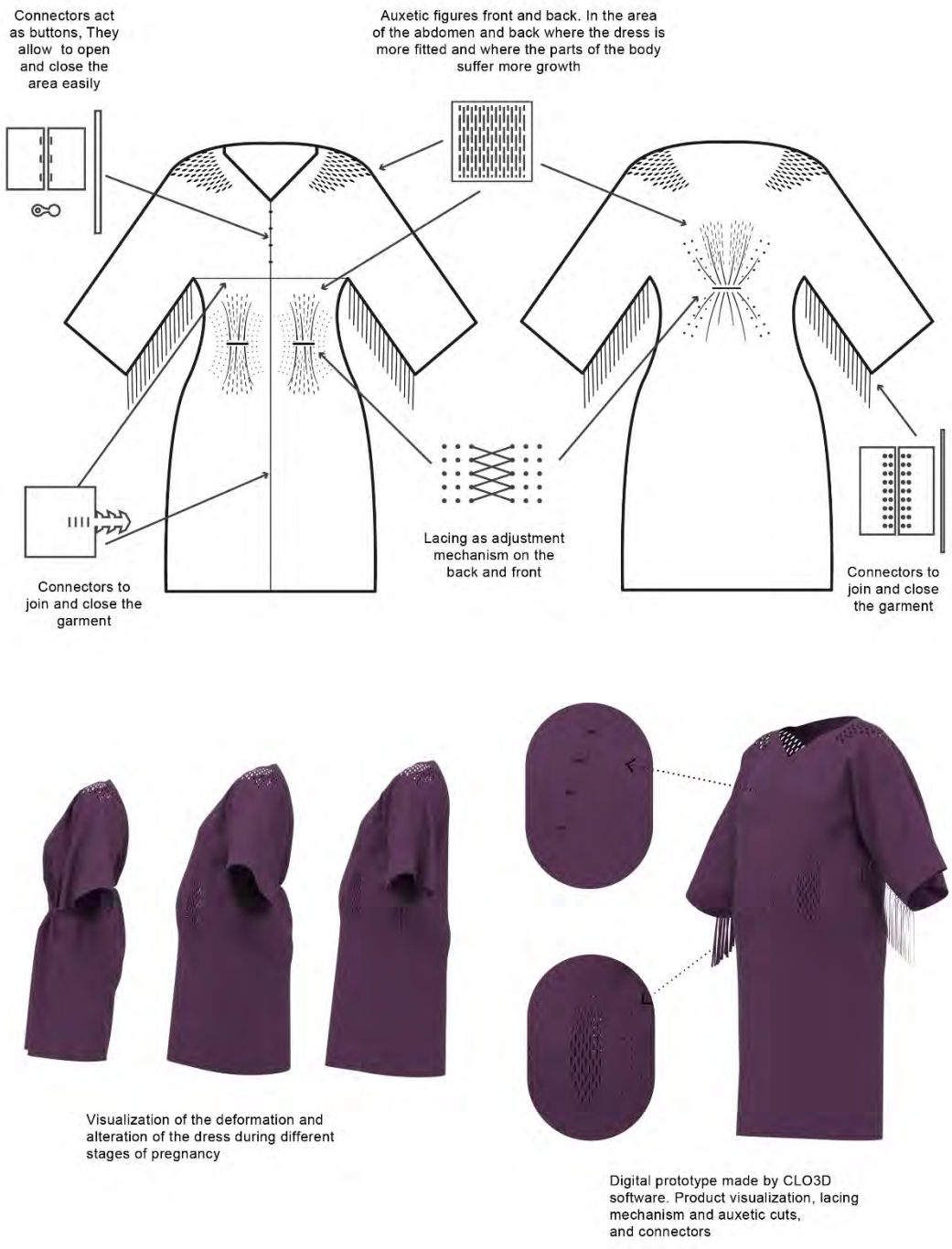


Figure 3. Dress to be produced by networking production with connectors

Both dresses are based on a zero-waste design created by the Make/Use tool (McQuillan, et al., 2018). This tool is adaptable to an extensive range of sizes and can include vast body diversity (McQuillan, et al., 2018). The pattern and design of the dresses are intended to be simple to be adaptable to different occasions. The dresses were developed through virtual prototyping technology, using CLO3D software that allows to test and modify the prototypes, visualise the garment fitting through the different stages of the pregnancy, and could be also exploited to offer a virtual tailoring experience on the service (Jankoska, 2021). We designed both dresses to be produced by laser-cut technology that reduces the garment production to only one step through a technology that is accessible worldwide in Fablabs laboratories (Nayak & Padhye, 2016). These two features make the

customization of the garments by the user feasible in terms of production costs and product lifecycle management.

The traditional model of serial production of finished products is replaced by the on-demand co-design model through a digital platform that allows a semi-finished designed product to be modified, customised, and finished by the consumers (Ambrosio & Vezzoli, 2019). Based on the user-centred research that highlighted the need for women to search for alternatives to feel more comfortable when buying clothes and accessories during pregnancy, we designed a user experience that intends to improve the purchase experience through the personalization of the product and the visualisation of the product on the user's avatars. The user experience consists of implementing a digital customer journey on a digital platform (Figure 4) allowing the user to co-design (selecting the zero-waste dress of their choice, choosing the type of production, and selecting predetermined alterations in terms of colours, materials, auxetic structure typology), customise the garment based on their measurements and preferences (through a questionnaire about their measurements) visualise and test (on a digital personal avatar through a virtual fitting session with the help of a real-time 3D rendered image) test and finally produce the customised product in a traditional or networking modality.

Figure 4. Platform design to customize the dresses.

Conclusion and Discussion

The study highlights the importance of producing adaptable, flexible, and sustainable garments for pregnancy through an inclusive approach at the design and manufacturing levels. The majority of surveyed women indicated the need of finding evolutionary garments that could fit their bodies in every stage of the pregnancy. The found alternatives such as oversized, loose, and shapeless clothing were found to negatively influence their self-esteem and body appreciation. The developed dresses with auxetic structures and lacing mechanisms can follow body changes during/after pregnancy with the ability both to control the garment and adjust the fabric during the different stages of pregnancy and also after, both feeling comfortable and perfecting the fit to their dynamic body changes with an excellent aesthetic appearance, thus allowing increased confidence and body satisfaction.

The manufacturing and co-design service through the digital platform allows a more democratic and inclusive process, allowing accessibility and customizability with a certain degree of freedom. The platform helps to create a no discriminatory product that includes the user as a cocreator toward a garment design and production that can create an attachment between people and garment, thus ensuring the product life extension (Maldini,2016). In addition to this, virtual size and fit platform technologies can help women have a better customer experience, through an interactive protected virtual space that allows custom fitting in a secure way, contributing to feeling more comfortable and gaining confidence and self-esteem.

In terms of environmental sustainability, the adaptable design also reduces the waste of clothes and prolongs their use not only during but also after pregnancy. In addition to this, the implementation of connectors on maternity clothes can decrease the ecological impact of the traditional production based on sewing and accessories inclusions. Connectors help to disassemble the product easily (without any mechanical or chemical process required) and also to eventually substitute some parts with a modularity logic. However, real environmental sustainability can be reached only when thinking in terms of systems, including innovative ways of manufacturing and selling. Here the on-demand networking production is a winning solution since it significantly allows a reduction of the garments' impact on the environment. On-demand self-production (Ambrosio & Vezzoli, 2019) minimises the number of resources needed, the cost of production, packaging, transport, and the waste from unsold finished goods. Furthermore, the diffused networking production on micro-urban scales promotes social interaction in local communities and creates local employment thanks to reshoring through a 0-km diffused production. However networked production needs further to be studied to overcome design limitations, logistics implementation, supply chain organisation, and users' involvement feedback.

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A Qualitative Analysis of the Challenges for Women with Physical Disabilities When Buying Fashion Online and In-store

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The act of dressing and finding clothing that accommodates both style and functional needs for many people with disabilities (PWD) is an arduous experience. Consumers with disabilities have very limited opportunities in ready-to-wear clothing to access functional yet attractive garments (Carroll and Gross, 2010; Bennet et al., 2019). From navigating the shopping experience to identifying particular clothes, access to accessible yet stylish clothing still remains a barrier to equality for PWD. In response, this study identified the challenges when finding appropriate clothing for women with varying physical disabilities that meet both functional and aesthetic needs. Fifty semi-structured interviews with women with physical disabilities reveal personal shopping experiences and the barriers to finding and wearing clothes. The study was analysed using a thematic method with results that revealed the most significant challenge when finding and wearing clothing were shoes (58%) and trousers (53%). When purchasing clothing, most participants preferred to see and feel the clothes physically; however, a majority expressed barriers to brick and mortar shopping because of inaccessible changing rooms (52%), physical exhaustion (40%), and problems accessing the store (22%). Finally, this study presents suggestive improvements to the shopping and dressing experience that contributes to raising awareness of fashion barriers faced by people with physical disabilities.

Keywords: *fashion; disability; user experience; inclusive design*

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Introduction

A person may have multiple disabilities, and many of our participants identified as such. To better understand barriers throughout a shopping experience, our research examines the online and offline challenges for women with physical disabilities. An inaccessible shopping experience may include physical barriers in store, or online websites that do not include accessibility app functionality. Furthermore, social stigmas reinforce inaccessible shopping, for example, assumptions that PWD do not shop for fashion. For PWD to be seen as *valued customers*, they must be seen as *customers*. Visibility of PWD, therefore, needs to be seen in all aspects of social and daily life to help normalise disability (Johnson and Kennedy, 2020) - an experience that most of us are likely to experience at one point in our lives, whether through injury, congenitally or old age (Seo and Fiore, 2016). For PWD, shopping usually starts with online research, to understand if a store and the journey to get to the store is accessible and will have what they want (Eskyté, 2019). When arriving at the store, barriers in accessing the physical store (Swaine *et al*., 2014) include finding an accessible entrance (Wertans and Burch, 2022). Once in the store, navigating complicated store layouts with narrow aisles can be hazardous. Finally, trying on clothing can be barred by inaccessible changing rooms that have not considered needs for assistance or adjustable seating. Due to challenges trying on clothing in stores, many participants prefered to try items on at home. PWD who do not have independence when leaving their home can find the returning process an arduous task. Online shopping poses many of the same challenges when it comes to unwanted items, regardless if the clothing meets the wearer's needs. From literature review, there is a lack of disability garment shopping research. Therefore, our paper emphasises challenges in the clothing shopping experience for women with physical disabilities.

Methods

Study Design & Participants

This is a qualitative study (Merriam and Tisdell, 2015) based on a grounded theory approach (Strauss and Corbin, 1994). Fifty semi-structured interviews were conducted with women with a range of physical disabilities ages 18-66. Participants were predominantly from the US and were recruited through posts on Facebook related to disability and mobility aid support groups. Written consent was provided, and the interviews were conducted online, lasting between 20 to 70 minutes. The participants were asked about their experiences with finding and wearing clothing, including questions about identity, fashion representation and personal aspirations when it came to style and clothing.

Data Reduction

All interviews were video recorded and transcribed verbatim. They were reviewed by two coders who did a content analysis, extracting quotes to identify high-frequency themes. All quotes were placed in a shared database where a third party analysed the content, identifying relevant themes and tagging each quote into three themes, labelled as social, political, and product. All quotes relevant to the shopping experience were reviewed a third time to find themes within this category, and clustered according to recurring themes and topics. Themes included barriers to shopping in-store and online, purchasing habits, as well as processes that helped work around shopping challenges.

Reflection and Review

After analysing all the data, a follow-up focus group was conducted where 14 individuals were split into four groups in order to share and discuss 'favourite brands' and 'how to improve the shopping experience' with one another. All focus groups were recorded and sessions transcribed into a combined list of shopping improvement suggestions.

Results

In-store Shopping Experience

While there are benefits of made-to-order online shopping for PWD who have faced barriers in the physical shopping experience, there is still a desire to experience materials and fit in-person. Being able to try on, test, and physically interact with garments gives consumers a more considered and accurate understanding of products to then choose from. 30% of interviewees emphasised material concerns, and 37% highlighted fit and sizing issues when searching for new clothing. This data demonstrates two significant factors when choosing in-store experiences over e-commerce options. However, there are still a variety of obstacles in physical retail spaces for PWD.

Navigating the Store

The architecture and interior design of retail outlets was a topic that repeatedly arose in the interviews and in literature (Goodrich and Ramsey, 2012; Kaufman-Scarborough, 1999). *''Some shops you can't even get into because it's got a step. It's not adapted for a wheelchair,"* described an interviewee. Another participant noted that a shop is*'' not accessible if you have a gigantic rug right in front of your doorway. I can't get enough leverage to get over it."* Architectural regulations such as the US Americans with Disabilities Act (1990) (Bungartz, 2022) and the UK Equality Act (2010) (www.equalityhumanrights.com, 2020), are a significant step forward for disability justice and accessible design of public space. Despite this legal progress, there are loopholes and many establishments do not adhere to these regulations. Steps, uneven flooring, revolving doors, and steep ramps are just a few barriers that spatially segregate PWD from participating and being seen as desirable consumers in shopping spaces. However, sliding doors, handrails and working lifts are great examples of accessible architectural solutions (Norman, 1988).

Having room to navigate shops with ease is incredibly beneficial for multiple consumers. For example, women bringing strollers may face aisle barriers when shopping, similar to PWD when using a wheelchair. One interviewee explains the stressful experience of shopping for clothing, *''Compared to somewhere like a bookstore or grocery store which have regimented, straight aisles of uniform width, clothing stores have their garment rails laid out in a random, uneven way, which makes it difficult to negotiate when using a wheelchair."* 18% of participants mentioned similar frustrations when navigating in shops. Most stores are designed to encourage product interaction, however, that usually entails mirrors and narrow aisles, which can be confusing, tiring, and even hazardous for PWD. Additionally, products are often placed out of reach and/or out of sight for those with visual impairments, those who are seated and/or with a shorter build.

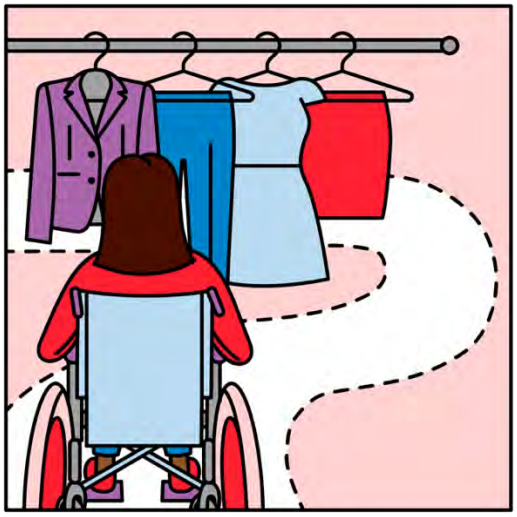

Figure 1. The winding aisles of a shop floor

Changing Room

The study reveals 52% of participants highlighted the design and experience of in-store changing rooms as another significant limitation when finding clothing. Trying on garments is highly appealing when in-store shopping, but without functional spaces to do so, this benefit becomes obsolete. *''It's really stressful if I go to a store because their changing rooms don't have seating. There's no seating or the seat is too low, or it's just a small stool like a pathetic little tiny dinky metal tin stool. It's not enough to hold my weight or anything else, it's terrible,"* describes one interviewee. As well as a lack of appropriate seating options, changing rooms are usually too small to fit assistive devices inside and don't have bars for support. Due to the lack of, poor design and misuse of disabled changing rooms, some PWD have found inventive ways to operate around these limitations. One participant explained that they *''never try pants on, it's too hard. So I'll just bring a pair of pants that I have that fit good, and then I'll compare them in the store. We'll hold them up and compare the size and then I will usually buy them and bring them home, try them on and if they don't fit right then I'll take them back."* While the participant demonstrates a strategic shopping solution, this further increases the time and energy spent shopping.

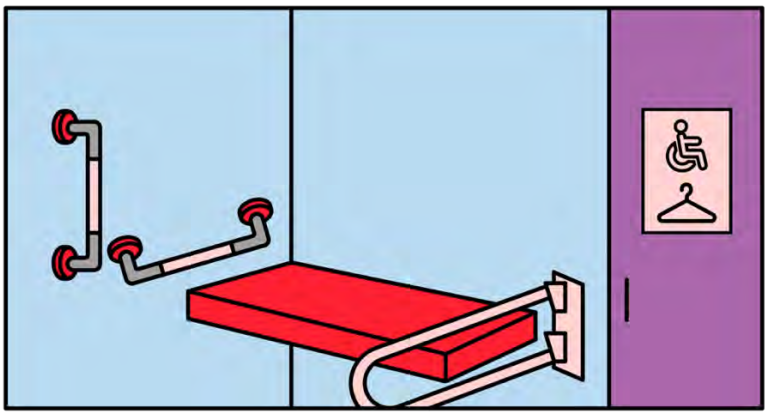

Figure 2. An accessible changing room with multiple handles and a long bench

Assistance

Many people with disabilities usually bring a family member, friend, or carer with them when shopping. 26% of the women interviewed needed assistance while dressing. One participant stresses the need for physical support from others, *''On a rare occasion I will try things on in shops, but I then need two people to help because you often cannot take the hoist into public places."* The 'disability politics of interdependence' (Hamraie and Fritsch, 2019) is a practice used by PWD to support each other through acts of care, such as shopping together. Another interviewee describes this co-buying act in more detail, *''My mother knows my issues, and she knows what flatters me. If she is in a store and she finds something that she knows will work for me, she will buy it."* Co-buying and co-dressing strategies can be mutually supportive practices that have physical and emotional benefits.

When shopping alone, PWD may have to rely on other people's willingness and availability to join them on shopping excursions in-store. Professional assistance is a missed opportunity when shopping in person. Many participants discussed the benefits of having experienced, knowledgeable and approachable retail staff that can help when searching for clothing both in-store and online. Other than brand and product knowledge, retail staff who have training in identifying functional and stylish preferences for PWD is essential.

Social Stigma

Other than physical barriers in the built environment, social stigma and ableism also poses challenges to in-person shopping for PWD. 35 out of 50 participant responses mentioned the stigma associated with shopping which discourages them from returning. One recurring negative social experience shared was people staring, *''Shopping is quite traumatising because people obviously stare, so that makes it a bit uncomfortable. You don't really feel confident with the stuff you're picking out because someone's staring at you."* Feelings of self-consciousness can deter people from shopping in-person. Because of the multiple physical and emotional barriers to in-person shopping, many PWD opt to order online, despite the shortcomings in that process. If less PWD are seen in shops as desirable consumers, ableism and lack of representation increases.

Exhaustion

A common response from the majority of participants was feeling physically and emotionally drained. 40% of the people interviewed noted that they found the shopping experience 'tiring', and 20% described it as 'stressful' *''most of the time shopping is not an enjoyable experience for people with disabilities, it's more of a job to find the right gear."* Unlike other clothing categories such as 'maternity wear' or 'plus-size', 'adaptive' clothing hasn't yet scaled in mainstream commercial fashion industries. A lack of product options often force PWD to visit multiple stores. One interviewee refers to their struggle finding trousers, *''If I'm going to buy pants, it's a whole day, a whole event. I have to emotionally prepare myself because I know I'm gonna be upset. And it's gonna be frustrating."* PWD have to visit multiple retailers to find clothing that might suit their functional or aesthetic needs, often finding garments that are accidentally adaptive rather than clearly labelled and categorised. The additional time and pre-planning taken in this process is a significant hindrance in the in-person shopping experience.

Online Shopping

Sizing

When shopping online, identifying the appropriate size and right fit is a gamble, says one participant: *''When I buy clothes online, they're either too big or too small, or an uncomfortable fit."* This is largely due to brand manipulation (Dockterman, 2022) and inconsistency in sizing charts (Clifford, 2022). For example, vanity sizing practices and discrepancies within products. One participant stated, *''I think everybody has difficulties when you order from a store and you don't know what you're getting."* Those with asymmetrical body types that are not typically considered in clothing design are faced with limited options. This need has been recognised by some in the shoe industry, such as Zappos Adaptive and Nike's 'Single Shoe Program' (www.zappos.com, n.d.), offering innovative strategies for consumers to buy two different size shoes.

Material Concerns

Elasticity in fabric can make a major difference when it comes to comfort and ease of donning and doffing, and for many PWD the ability to *''feel out the materials to make sure that it's stretchy enough",* is very important. In our study, 30% of participants' concerns centred around not being able to feel the fabric or material when online shopping. Other questions about garment construction, such as understanding where seams and tags are placed on the product to avoid irritation and pressure sores, were also raised in interview discussions. One participant noted, *''I'm always going round in shops and feeling the waist bands of trousers, especially jeans to see how rough the stitching is."* Shoes in particular are a product that needed to be tried on in person, for example one interviewee describes the need to *''feel the soles, to make sure it's grippy."* The tactility and feeling when trying on clothing or accessories is a concern for not just the women with disabilities but for many shoppers. The barriers to returning such items is the difference.

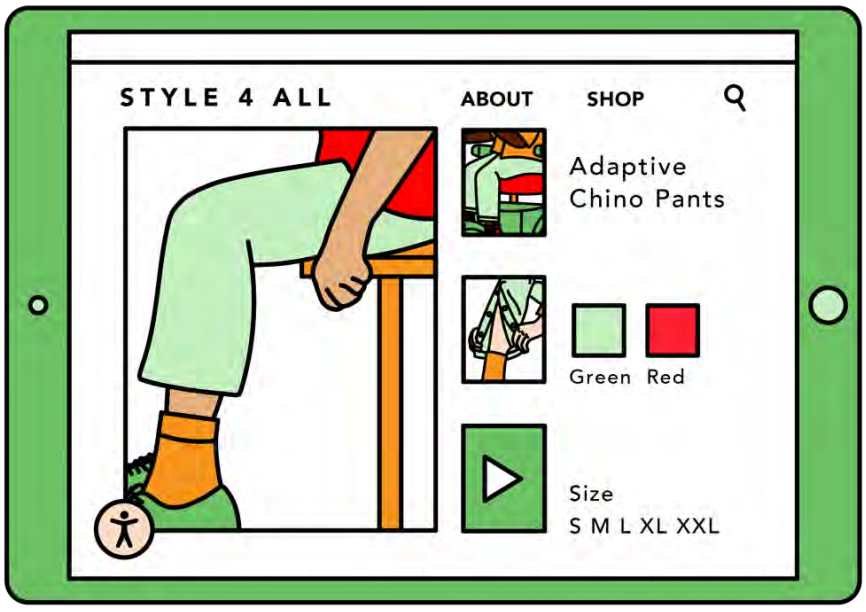

Figure 3. A fictional illustration of an accessible website which shows features such as openings / closures, a seated model and a video of the material

Logistics

Organising the delivery and return of items was the top barrier identified by 43% of interviewees when shopping online. Participants were more likely to return or exchange a product that lacked or didn't provide accurate information. *''Online, my proportions are weird, I just feel like finding things that fit is a real challenge and so the back and forth of returning stuff is exhausting and I just can't be bothered."* For many PWD who struggle to leave their home without assistance, the logistics of having to post or return an item in-store combined with the chance that items will be delivered in a hard-to-collect location is even more challenging. Another participant remarks, that *''they [delivery person] leave it downstairs and how am I going to get it upstairs when I can't carry and walk at the same time?"* Some of the opportunities to address logistics include brand familiarity, finding accessible second-hand products and bulk purchasing.

Purchasing Habits

Brand Familiarity

For PWD, brand knowledge can help relieve sizing, material, and logistical concerns both in-person and online. For example, brand familiarity includes sizing knowledge, fabrics that work well for an individual's body or being comfortable with the accessible entry points to a physical store. 10% of participants mentioned the importance of brand familiarity, expressing that it is *''very difficult when you are experimenting with a new brand because of the high energy exertion and financial risk if it does not work."* Once a customer understands and has a relationship with a brand, this translates into a less anxious physical shopping experience. Furthermore, this increases the purchasing confidence in PWD when buying a product online: *''I don't like shopping online, if there is a specific brand that I know their sizing, then I might buy stuff online."* Because of a lack of options and difficulty finding adaptive clothes, PWD are loyal returning customers when identifying a brand that works for them. For example, one participant expressed *''when I am familiar with a brand, I know what works for me - I rarely don't come out with a bag of clothes."* Brand loyalty provides retailers with the opportunity to connect with disabled consumers.

Purchasing Second Hand

Accessible clothing and accessories that work for individual style and disability needs are rare. PWD are likely to *''buy [accessible clothing] in a few different colours, because it's hard to find things to get on."* Another participant searched *''eBay for the exact pair [of jeans] again and again".* Especially if a product is discontinued, PWD will be loyal to brands and products that they can rely on. One interviewee described finding a pair of trousers that worked for her needs but were discontinued: *''[The pants] were ultra-skinny, ultra-soft and had a really soft waistband and stitching. But Primark doesn't make them anymore, so I'm going on Ebay and I'm buying up all the pairs I can get my hands on because I know they've got to last me for the rest of my life."* Despite the challenges and frustrations in online shopping, brand loyalty and bulk purchases of favourite products are key to removing some of the barriers for PWD.

Bulk Purchasing

The option to over-order online to try on more comfortably at home and then return the product has been a strategy for participants. Bulk purchasing can also be an

alternative to in-person shopping. One participant highlighted that *"I do put a lot of thought and care, and I will spend $1,000 on Zappos to order ten pairs of shoes knowing I will only keep one because it is so hard to find footwear."* However, this option is limited to those who cannot easily return items nor have the financial capital to purchase in bulk. Financial means was also a topic that arose from the data. Not every participant could afford to purchase different sizes and a range of colours at once.

Limitations

This study was conducted with a specific demographic of 50 women predominantly in the US with physical disabilities, and therefore the findings are a direct correlation of their lived experiences. There are of course a variety of PWD that have very different wants and needs, and this paper doesn't claim to speak for the experience of PWD as a whole. The subject matter of the interviews was also semi-structured, leaving some topics that weren't fully discussed, such as the journey to the store or sensory sensitivities when shopping. The participants may have also visited a wide variety of different retail outlets, from large modern shopping malls to small brick-and-mortar establishments. Finally, the interviewers were PWD and therefore may have had unconscious pre-existing biases on the topics.

Conclusion

The study demonstrates some of the factors that contribute to inaccessible in-person and online shopping in hopes to increase awareness and highlight areas of actionable solutions for the retail industry. When shopping in stores, participants mentioned four main topics as barriers to an inclusive shopping experience; accessing and navigating inside the shop, inaccessible changing rooms, assistance while dressing and social stigma. When shopping online, sizing, material concerns and the logistics of delivery and return were some of the biggest challenges to shopping online. These barriers can be minimised by brand familiarity, purchasing known-to-work items second-hand, and buying in bulk if financially able.

Fashion has the potential to expand people's self-expression. Shopping can be a liberating experience. Yet, current retail systems are still exclusionary, leaving many of the participants exhausted and filled with negative emotions. Making the shopping experience more inclusive can help fight stigmas, recognise PWD as desirable customers through visibility in social and daily life, and help fight ableist attitudes.

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Inclusive Shared Autonomous Vehicles

Identifying areas for inclusive design intervention

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Shared Autonomous Vehicles (SAVs) have the potential to improve mobility for a range of transport-excluded groups, allowing them better access to economic, social, educational, and health activities. While there are a number of benefits to SAVs for excluded groups, it is important that their needs are actively addressed in the design of these vehicles, services and infrastructure. In order to aid designers in the development of more inclusive SAVs, this paper presents a number of inclusive SAV design criteria that address the needs of multiple transport-excluded groups. By exploring literature considering existing experiences of people excluded from transport due to ageing, disability, gender, location, income, and ethnicity, a number of barriers were identified. These barriers were collated into general problem areas common to a number of groups. Finally, these general problem areas were used to develop multiple inclusive design criteria within 5 main areas for inclusive SAV design intervention. These 5 areas are interfaces and information, service, infrastructure, vehicle, and SAV operation. Considering the design criteria within each of these areas, designers can begin to develop SAV solutions that address the needs of multiple transport-excluded people groups and create more inclusive SAV services.

Keywords: *autonomous vehicles; shared mobility; inclusive design; transport-related social exclusion*

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Introduction

Various people groups experience transport exclusion due to factors including ageing, disability, gender, location, income, and ethnicity (Lucas, 2012). This exclusion from transport can have a series of knock-on effects with excluded groups being unable to access essential social, economic, health, and educational activities (Lucas, 2012).

The introduction of Shared Autonomous Vehicles (SAVs) promises a number of inherent inclusivity benefits by providing a driverless, door-to-door transport service for people without access to a private car due to disability, income etc. (Detjen *et al.*, 2021). These vehicles would operate as part of a service allowing for synchronous sharing- using the vehicle at the same time as others, and asynchronous sharing- using the vehicle privately, but not owning the vehicle. To ensure that these vehicles are as inclusive as possible, more attention needs to be paid to how these vehicles and services can be designed to address current issues of transport exclusion.

Studies have explored SAVs in the context of individual excluded groups, considering attitudes towards SAVs (Bennett, Vijaygopal and Kottasz, 2019a, 2019b, 2020; Brinkley *et al.*, 2020), using participatory design methods to explore specific needs of excluded groups (Brewer and Kameswaran, 2018) and using full scale SAV mock-ups to test accessibility of SAVs with disabled people (Wasser *et al.*, 2018; Tabattanon, Schuler and D'Souza, 2020). Other studies have explored transport exclusion by categorising it into different groups of barriers (Church, Frost and Sullivan, 2000; Mackett and Thoreau, 2015; Severs *et al.*, 2021). Less has been done, however, to understand the crossover in these exclusionary factors among different excluded groups and to group excluding factors with regard to the way that inclusive design could be used to address them.

Because SAVs only currently exist as prototypes and trials, literature exploring excluded groups' experiences of these vehicles is limited. This paper instead focuses on how existing experiences of exclusion in transport services can be used to anticipate exclusion within SAV services, and how SAVs can be designed to improve on existing transport services by addressing existing exclusion.

This paper presents a synthesis of data from literature looking at existing experiences of transport among people excluded due to ageing, disability, gender, location, income, and ethnicity. Through this synthesis we identify a number of SAV design criteria within 5 areas of inclusive SAV design intervention: *Service, Infrastructure, SAV Operation, Vehicle Design, and Information and Interfaces* and identify some of the ways in which SAV services may inherently address some issues of exclusion.

By taking an Inclusive Design for Transport approach (Severs *et al.*, 2021), this paper includes research focusing on the needs of groups beyond the age-ability construct and ensures that issues of usability, availability and experience are all included in discussions of inclusivity. Due to the potential for specially adapted vehicles within transport services (e.g. accessible taxis) to cause exclusion for groups due to lack of availability (Wong *et al.*, 2020), the design criteria detailed in this paper present opportunities for design that can be applied to every SAV within a service.

This paper ultimately seeks to answer the research question: How might inclusive design interventions be used in the development of SAVs to ensure that each vehicle and the service itself meets the needs of a broad spectrum of people?

Methods: Synthesis of design criteria

An initial study of literature considered a range of focus group and survey studies with members of different excluded groups, as well as grey literature such as reports from organisations involved in advocating for the needs of transport-excluded groups. This data was collected as individual issues of transport exclusion relating to each group and sorted into four broad categories to make the data more manageable. These categories are *service*, *infrastructure & built environment*, *vehicle,* and *digital & information*. These categories were generated based on a thematic review from an initial reading of the literature, and from categories used in some of the studies considered e.g. *service* from Park and Chowdhury (2018)

A process of data synthesis was then used to translate these individual issues of exclusion into general problem areas common to multiple groups (Figure 1). These general problem areas were used to generate individual design criteria where the design of SAVs may be able to address these barriers.

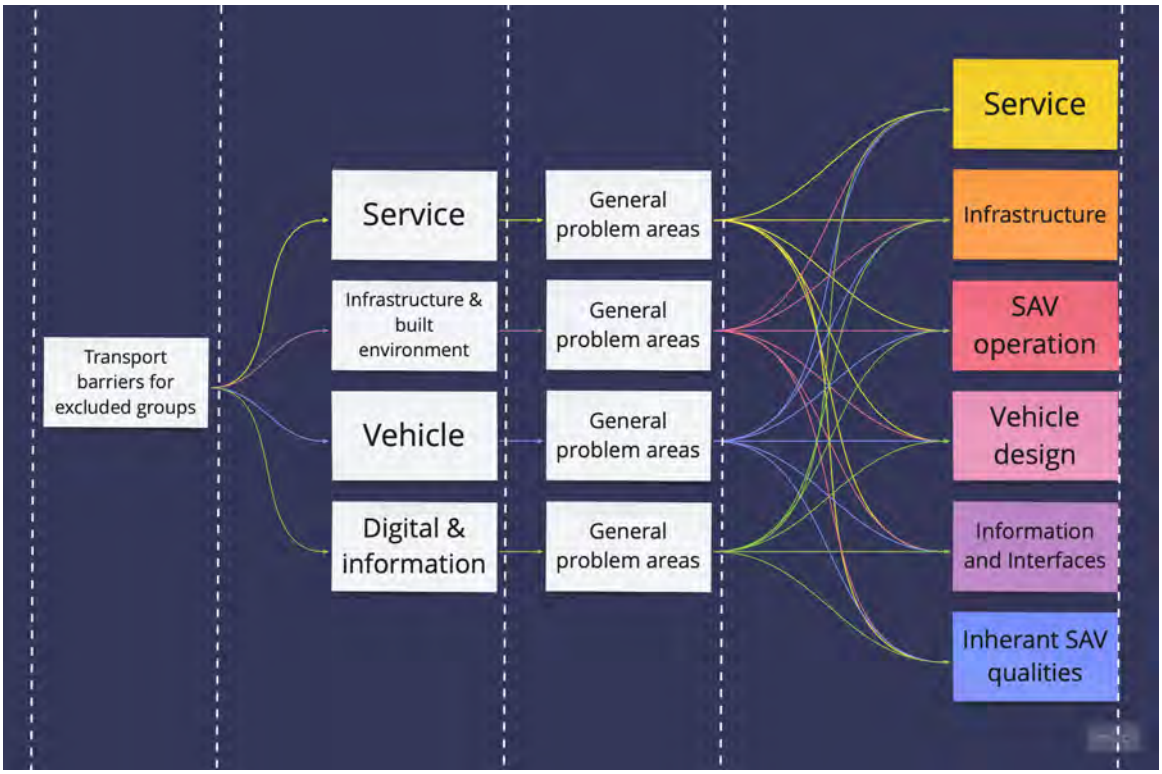

Figure 1: Process of synthesis from initial barriers to design criteria within 5 areas of intervention

These design criteria were then sorted into 5 broad areas of inclusive SAV design intervention: *Service, Infrastructure, SAV Operation, Vehicle Design, and Information and Interfaces*. These groupings were created so that stakeholders involved in each of these areas of SAV development can be made aware of the range of ways in which they can contribute to creating more inclusive SAV services. One additional category, *Inherent SAV qualities*, was also added in order to include the ways in which SAVs already address some barriers.

This process of synthesis was mapped using Miro (an online whiteboard software) to retain each step of the process and allow the detail of the initial barriers to be accessed when designing solutions. Figures 2-5 show these maps and Tables 1-4 contain examples of the individual barriers collected from the literature

corresponding to the codes on the first set of lines. The numbers in the design criteria sections link to the criteria detailed in the following section.

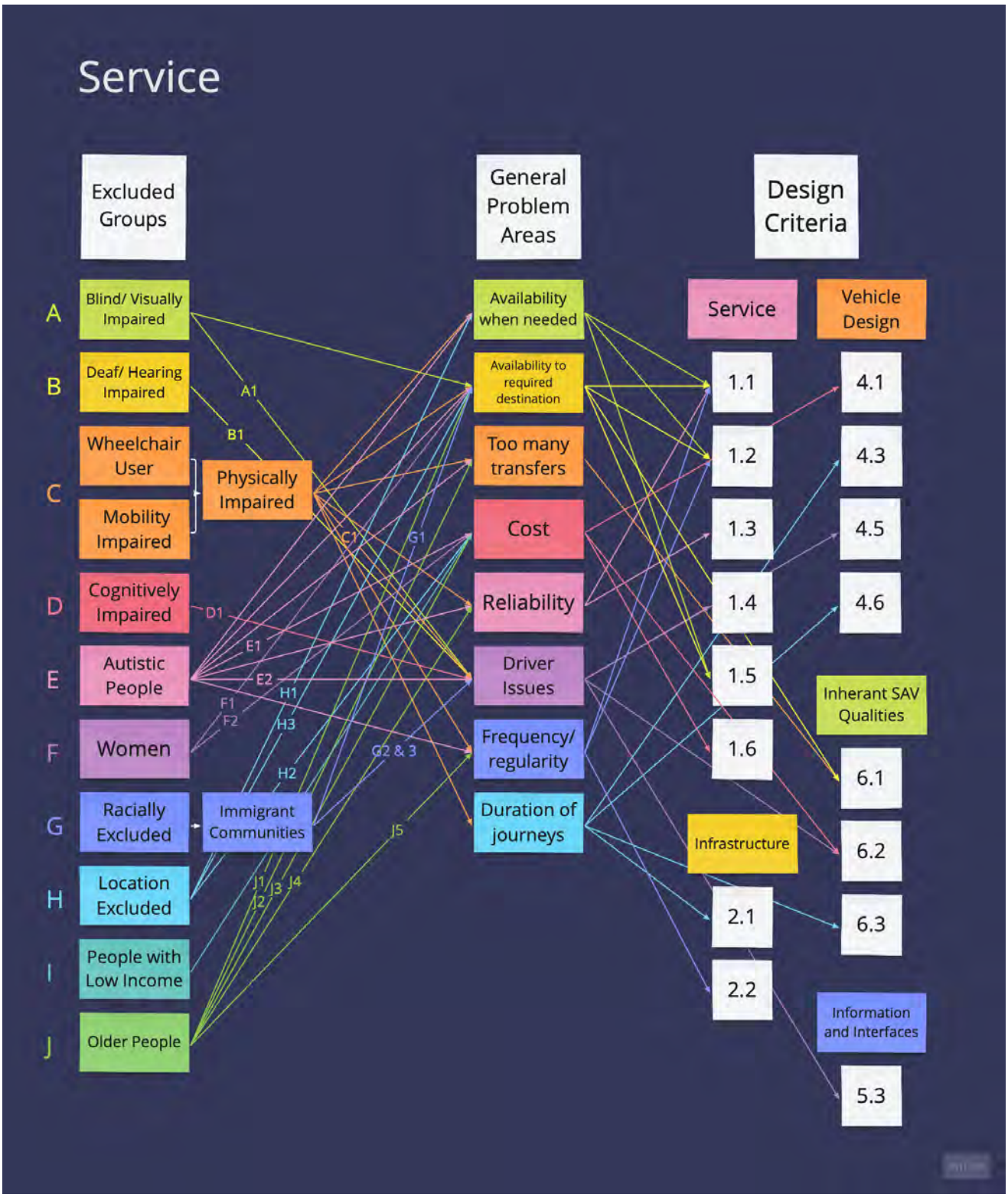

Figure 2 Miro board mapping development of inclusive SAV design criteria related to service-based barriers

Table 1. Descriptions of specific exclusionary barriers from Figure 2

Code	Description of barrier from literature
A1	Poor attitude and awareness, bus not stopping, language barrier; poor training and awareness (Park and Chowdhury, 2018)
B1	Poor training and awareness (Fürst and Vogelauer, 2012)
C1	Poor attitude and awareness, bus not stopping (Park and Chowdhury, 2018)
C2	Wheelchair users waiting for bus that allows them to board (Velho, 2019)
D1	Poor communication and provision of information, bus not stopping, driving behaviour- hard breaking etc. (Risser, Iwarsson and Ståhl, 2012)
E1	Costly fares (Deka, Feeley and Lubin, 2016)
E2	Worried about driver behaviour (Deka, Feeley and Lubin, 2016)
F1	Transport routes favouring types of journeys men are more likely to take e.g. commuting and not the shorter journeys women are more likely to take for caring roles (Gill, 2018)
F2	More likely to be in part-time work therefore missing out on transport savings from season tickets and passes (Gill, 2018)
G1	Transport routing not taking into account journey need to connect immigrant communities (Schachter and Liu, 2005)
G2	Communication with driver in second language, racism (Schachter and Liu, 2005)
G3	Uber, Lyft allowing for driver biases to dictate whether a passenger gets to use the service (Ge *et al.*, 2016)
H1	Poor provision (Velaga *et al.*, 2012)
H2	Rising costs of transport services (Allen, 2020)
H3	Decreasing level of service (Allen, 2020)
J1	Existing transport routes favouring commuting, fewer older people work, more likely to make journeys across communities (Centre for Ageing Better, 2019)
J2	Having to change modes (Gilhooly, Hamilton and O'Neill, 2002)
J3	Cost of more flexible modes of transport is higher (Centre for Ageing Better, 2019)
J4	Service running late/ cancellations (Gilhooly, Hamilton and O'Neill, 2002)
J5	Having to wait (Gilhooly, Hamilton and O'Neill, 2002)

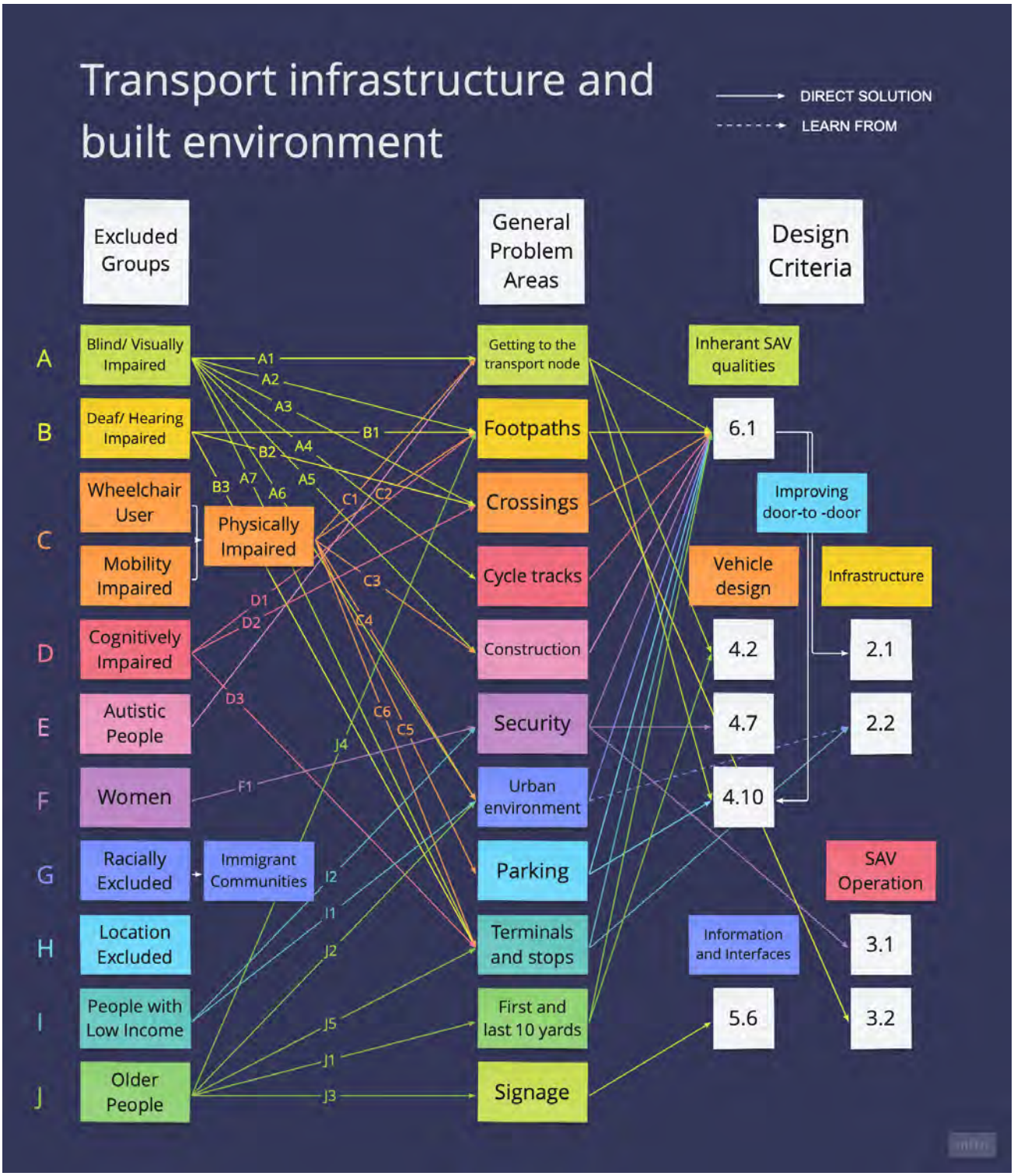

Figure 3: Miro board mapping development of inclusive design for SAV design criteria related to transport infrastructure and built environment based issues

Table 2. Descriptions of specific exclusionary barriers from Figure 3

Code	Description of barrier from literature
A1	Distance to travel to and from vehicle (Park and Chowdhury, 2018)
A2	Obstructions, uneven surfaces, poor lighting, lack of footpaths, lack of tactile surfaces, lack of contrast marking (Fürst and Vogelauer, 2012; Park and Chowdhury, 2018)
A3	Railway crossings without gates, tactile surfaces and lighting (Fürst and Vogelauer, 2012)
A4	Not easily visible distinction between pedestrian and cycle path (Fürst and Vogelauer, 2012)
A5	Footpath closures, cones obstructing path, removal of tactile paving, noise, scaffolding, lack of solid barriers (Fürst and Vogelauer, 2012; Park and Chowdhury, 2018)
A6	Obstruction by bollards, hydrants, advertising pillars, cars, restaurant tables and menus; need for contrasting colours (Fürst and Vogelauer, 2012)
A7	Lack of shelters, steep ramps, lack of lifts, lack of toilets, gap between vehicle and platform (Park and Chowdhury, 2018)
B1	Uneven surfaces, gaps (Fürst and Vogelauer, 2012)
B2	Railway crossings without gates and lighting (Fürst and Vogelauer, 2012)
B3	Need for emergency button for HI people in lifts (Fürst and Vogelauer, 2012)
C1	Distance to travel to and from vehicle (Park and Chowdhury, 2018)
C2	Obstructions, uneven surfaces (Park and Chowdhury, 2018)
C3	Temporary walkways (Park and Chowdhury, 2018)
C4	Steep gradients, hills, curbs, crossing roads, security on journey (Park and Chowdhury, 2018)
C5	Lack of accessible parking at stations (Park and Chowdhury, 2018)
C6	Lack of shelters, steep ramps, lack of lifts, lack of toilets, gap between vehicle and platform (Park and Chowdhury, 2018)
D1	Poor maintenance of pedestrian environment, uneven surfaces (Risser, Iwarsson and Ståhl, 2012)
D2	Poor placement/ location (Risser, Iwarsson and Ståhl, 2012)
D3	Poor positioning (Risser, Iwarsson and Ståhl, 2012)
F1	Fear of being alone in car parks, underground stations and railway platforms (European Commission. Directorate General for Mobility and Transport., 2014)
I1	Poor state of environment for walking (Bostock, 2001)
I2	Security & safety when walking with children (Bostock, 2001)
J1	Door-to-vehicle, first and last 10 yards (Centre for Ageing Better, 2019)
J2	Lack of facilities including toilets, seating etc. (Centre for Ageing Better, 2019)
J3	Lack of good signage (Centre for Ageing Better, 2019)
J4	Poor pavement quality (Centre for Ageing Better, 2019)
J5	Being out in bad weather (Gilhooly, Hamilton and O'Neill, 2002)

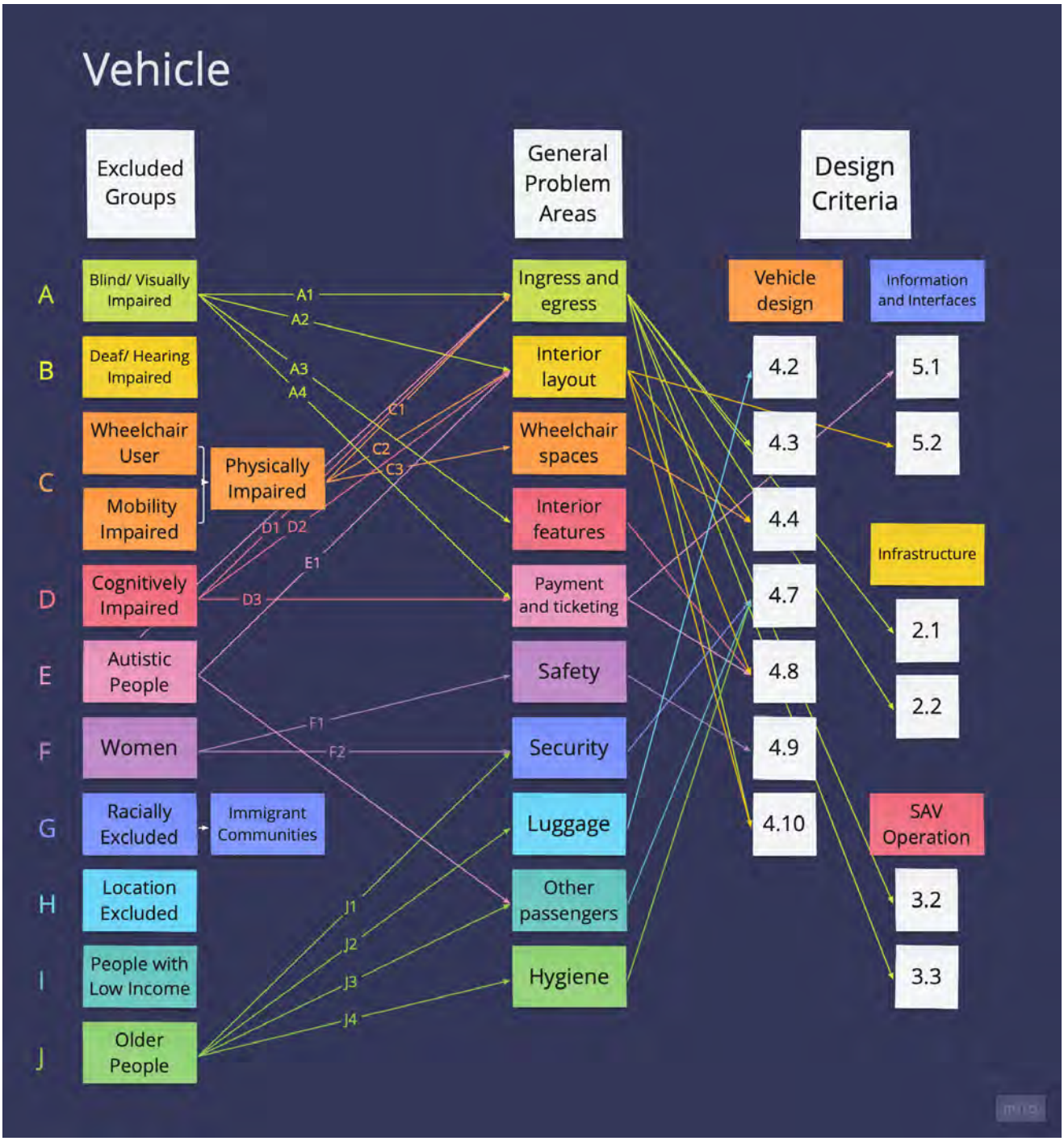

Figure 4: Miro board mapping development of inclusive design for SAV design criteria related to vehicle-based issues

Table 3. Descriptions of specific exclusionary barriers from Figure 4

Code	Description of barrier from literature
A1	Distance from vehicle to kerb (Fürst and Vogelauer, 2012)
A2	Steps onboard, seats too close together, buzzers not in same location, lack of contrasting colours on edges; need for low-floor-vehicles (Fürst and Vogelauer, 2012; Park and Chowdhury, 2018)
A3	Faulty stop buttons; need for large tactile door buttons (Fürst and Vogelauer, 2012; Park and Chowdhury, 2018)
A4	Audio feedback not loud enough; Need for voice output and larger font size (Fürst and Vogelauer, 2012; Park and Chowdhury, 2018)
C1	Too steep, lack of kneeling feature on buses (Park and Chowdhury, 2018)
C2	Narrow buses, inadequate space, steps onboard (Park and Chowdhury, 2018)
C3	Inadequate wheelchair restraints (Park and Chowdhury, 2018)
D1	High steps, kneeling function not used, stopping far away from kerbs, heavy breaking and accelerating when standing to disembark. Similar issues to PI people due to cognitive impairments often having PI comorbidities, post stroke etc. (Risser, Iwarsson and Ståhl, 2012)
D2	Navigating to seat when vehicle moving, visibility from seat making requesting a stop at the right moment difficult (Risser, Iwarsson and Ståhl, 2012)
D3	Location of ticket validation, buying a ticket, handling payment (Risser, Iwarsson and Ståhl, 2012)
E1	Worried about finding a seat (Deka, Feeley and Lubin, 2016)
F1	More vulnerable to injury due to vehicle design failing to account for differences in physiology between men and women (European Commission. Directorate General for Mobility and Transport., 2014)
F2	Not feeling safe travelling at night, alone, or in crowded transport services where sexual assault may occur (European Commission. Directorate General for Mobility and Transport., 2014)
J1	Personal security in evening and at night (Gilhooly, Hamilton and O'Neill, 2002)
J2	Difficulties carrying heavy loads (Gilhooly, Hamilton and O'Neill, 2002)
J3	Behaviour of some passengers (Gilhooly, Hamilton and O'Neill, 2002)
J4	Lack of cleanliness (Gilhooly, Hamilton and O'Neill, 2002)

Figure 5: Miro board mapping development of inclusive design for SAV design criteria related to digital and information based issues

Table 4. Descriptions of specific exclusionary barriers from Figure 5

Code	Description of barrier from literature
A1	Need for accessible, downloadable route planning for on-trip use (Fürst and Vogelauer, 2012)
A2	Poor contrast, small print; too far away, too high, small print, reflective glass, not enough information on displays, poor contrast (Fürst and Vogelauer, 2012; Park and Chowdhury, 2018)
A3	Lack of audio announcements on vehicles and at ticket machines; need for clear on-demand audio info (Fürst and Vogelauer, 2012; Park and Chowdhury, 2018)
A4	Lack of accessible real time info (Fürst and Vogelauer, 2012; Park and Chowdhury, 2018)
A5	Inadequate guiding systems, need for clear splitting of station areas for different lines, need for clearer markings and signage, need for clearly visible arrival information (Fürst and Vogelauer, 2012)
A6	Small text, poor contrast, lack of voice output (Fürst and Vogelauer, 2012)
A7	Illegible network plans- not at eye-level, too far away, not large enough, need for information in audio format ("two-senses-principle"), need for accessible on-demand information (Fürst and Vogelauer, 2012)
A8	Small text, lack of voice output (Fürst and Vogelauer, 2012)
B1	Need for accessible, downloadable route planning for on-trip use (Fürst and Vogelauer, 2012)
B2	Need for accessible, downloadable route planning for on-trip use (Fürst and Vogelauer, 2012)
B3	Lack of accessible real time info (Fürst and Vogelauer, 2012)
B4	Need for clearly visible arrival information (Fürst and Vogelauer, 2012)
B5	Need for information in visual format ("two-senses-principle"), need for accessible on-demand information (Fürst and Vogelauer, 2012)
B6	Need for visual alerts that can catch eye of HI people (Fürst and Vogelauer, 2012)
C1	Stigma from ramp alarm (Velho, 2019)
D1	Relying on others to plan trips, poor automated telephone planning service desire for a "human voice" (Risser, Iwarsson and Ståhl, 2012)
D2	Difficulties reading timetables and numbers, small print, difficulties remembering information, difficulties locating departure bus stop, regularly changing bus numbers (Risser, Iwarsson and Ståhl, 2012)
D3	Hard to understand (Risser, Iwarsson and Ståhl, 2012)
D4	Difficult to use pavement guidance systems- poor contrast and placement (Risser, Iwarsson and Ståhl, 2012)
E1	Difficulties with planning (Deka, Feeley and Lubin, 2016)
G1	Language barrier (minority of group) (Schachter and Liu, 2005)
G2	Hard to understand (Schachter and Liu, 2005)
G3	Instructions in second language (Schachter and Liu, 2005)
H1	Poor/ lack of real-time passenger information systems (Velaga *et al.*, 2012)
I1	Unbanked passengers unable to use contactless payment systems (Brakewood and Kocur, 2013)
J1	Over reliance on tech based booking, payment and ticketing (Centre for Ageing Better, 2019)

Results: Design criteria for inclusive SAVs

The following section describes the design criteria generated through the synthesis of data from the literature studied. These criteria relate to the design of physical aspects of the SAV service e.g. vehicle features, but also relate to the design of the service itself. Each criterion has a number to linking it to Figures 2-5 to demonstrate how the criteria were generated.

Service

The service area refers to any elements of the SAV service related to the administration and provision of the service, this includes staffing, timings, availability and pricing.

Inclusivity at the service level can address the ways that many people are excluded by poor availability of transport (Severs *et al.*, 2021). Groups currently experience exclusion as a result of service based factors such as people in rural areas experiencing poor provision of transport (Velaga *et al.*, 2012; Allen, 2020). Cost is another significant service-based excluding factor for a number of groups including those in rural areas, and women (Gill, 2018; Allen, 2020). Disabled people and those belonging to certain ethnic groups may also experience exclusion as a result of the actions and attitudes of drivers and staff such as racism and lack of awareness of disability (Deka, Feeley and Lubin, 2016; Ge *et al.*, 2016; Park and Chowdhury, 2018).

The following criteria relate to the design of the SAV service:

1.1 High number of inclusive SAVs in service- Making sure that there are enough inclusive SAVs in the service and that they all meet the needs of excluded groups.

1.2 Demand responsive- SAVs responding quickly to changes in demand can ensure that they are available when needed. This is particularly valuable in locations such as rural areas where transport services are not always immediately available. When developing demand responsive SAV services, it is important to ensure that these do not favour certain groups more than others. For example, there is a danger that these services may perpetuate gendered exclusions resulting from male-dominated journeys being better provided for than the journeys that women may be more likely to take.

1.3 Vehicles well maintained- Ensuring that SAVs are reliable and therefore available when needed, particularly in areas with fewer available vehicles.

1.4 Well trained staff- Ensuring that, if staff are part of the SAV service, they are aware of the needs of different excluded groups and do not serve to actively exclude them.

1.5 Available in underserved locations- Making sure that SAVs don't perpetuate location-based exclusion by being available in rural areas and other underserved locations.

1.6 Fairly priced- Addressing current issues of gendered and location based financial exclusion in transport and ensuring that SAV journey prices are kept low for all groups.

1.7 Availability of staff to assist with booking etc.- Making sure that staff are available to assist people with activities that inclusive design solutions may not be able to fully address.

Infrastructure

The infrastructure area includes criteria relating to the design of stops, stations and road infrastructure that may be used by the SAV service.

Certain groups currently experience exclusion as a result of waiting facilities not meeting their needs with places to sit and toilet facilities (Centre for Ageing Better, 2019), groups including older people and women also experience fear based exclusion while using waiting facilities (Gilhooly, Hamilton and O'Neill, 2002; European Commission. Directorate General for Mobility and Transport., 2014). Further exclusion occurs for disabled people- especially mobility & visually impaired people- as a result of pavements being obstructed (Fürst and Vogelauer, 2012; Risser, Iwarsson and Ståhl, 2012; Park and Chowdhury, 2018).

Inclusive infrastructure design may help to address other issues of transport exclusion, particularly issues related to boarding that affect a number of disabled groups and older people (Fürst and Vogelauer, 2012; Risser, Iwarsson and Ståhl, 2012; Park and Chowdhury, 2018). SAV infrastructure could also address issues related to the need to travel from the vehicle to your destination that many disabled groups face (Park and Chowdhury, 2018) by providing designated SAV spaces near key destinations.

The following criteria relate to the design of SAV infrastructure:

2.1 Dedicated space on roads for SAVs- Allowing SAVs to travel more efficiently and drop people closer to their destination.

2.2 Inclusive stops and stations- Making sure that excluded groups are able to wait comfortably and safely, and board the vehicle easily.

SAV operation

The SAV operation area is related to the way the vehicle drives and chooses routes in the absence of a driver.

In existing transport services certain excluded groups experience difficulties due to aggressive driving styles making moving within the vehicle difficult (Risser, Iwarsson and Ståhl, 2012), vehicles not stopping close to the kerb for easy boarding (Fürst and Vogelauer, 2012), and vehicles not stopping at all (Velho, 2019). The way that the SAV drives and operates has the potential to address some of these issues.

SAV operation may also be able to address some issues related to fear based exclusion experienced by groups such as women and older people by adjusting where the vehicle travels and stops and by giving passengers control over their journeys (Gilhooly, Hamilton and O'Neill, 2002; European Commission. Directorate General for Mobility and Transport., 2014).

The following criteria relate to the design of SAV operation:

3.1 Giving passengers control- Providing people with choices over the routes the vehicle takes and where it drops them off to ensure that they feel safe and secure.

3.2 Inclusive drop off locations- Making sure that SAVs drop people in areas that are safe, secure, easily accessible and close to their destination.

3.3 Considerate driving style- Ensuring that SAVs drive smoothly, stop close to the pavement and reducing the need for passengers to move around while the vehicle is moving by allowing them time to sit.

Vehicle design

The vehicle design area includes the physical aspects of the design of the vehicle, including interior layouts, seating, and more technical issues including the design of the vehicle architecture. This area also includes the physical location of interfaces within the vehicle, as these design decisions are more likely to occur when designing the vehicle interior than when designing the user interfaces themselves.

People currently experience exclusion in transport services due to the design of existing vehicles not meeting their needs with poor wheelchair occupancy, difficulty navigating inside, difficulty boarding, and insufficient space (Fürst and Vogelauer, 2012; Risser, Iwarsson and Ståhl, 2012; Park and Chowdhury, 2018). Certain groups also experience exclusion as a result of basic anthropometric and ergonomic differences not being considered in the design of seating and safety features (European Commission. Directorate General for Mobility and Transport., 2014).

As well as addressing these more obvious points of exclusion inclusive vehicle design may also be used to address issues of fear based exclusion caused by sharing vehicles with strangers (European Commission. Directorate General for Mobility and Transport., 2014).

The following criteria relate to the design of the shared autonomous vehicles, themselves:

4.1 Low cost of materials and manufacture- Keeping the cost of the vehicle low to increase the likelihood that journey prices may be lower for low income groups.

4.2 Inclusive storage solutions- Allowing for easy access to luggage storage and reducing the need to carry luggage onboard the vehicle. Providing designated storage for mobility aids and assistive devices.

4.3 Accessible boarding- Creating easier boarding options for disabled and older people with ramps, level-boarding, hand rails etc.

4.4 Inclusive interior layout- Ensuring that navigating within the vehicle is easy for disabled people, particularly those with visual and mobility impairments and that there is sufficient space for wheelchair users.

4.5 Features to replace role of driver in assisting passengers- The absence of the driver to assist excluded groups may cause further exclusion. Considering how these activities could be automated within the design of the vehicle itself may ensure new barriers are not created in the absence of a driver.

4.6 Inclusive provision for in-vehicle activities and entertainment- The *experience* dimension of the *Inclusive Design for Transport* approach may be addressed in the design of vehicles that facilitate excluded groups engaging in other on-journey activities.

4.7 Security for passengers- Creating interior spaces that feel safe to groups who may experience fear based exclusion. This may be achieved through interventions such as the division of the space and lighting.

4.8 Inclusive layout of interfaces and information- Locating interfaces within the vehicle in a way that is accessible to all users, e.g. at appropriate levels for wheelchair users and within easy reach of visually impaired people.

4.9 Inclusive ergonomics and anthropometrics- Ensuring that the dimensions of features such as seating, doors, luggage storage etc. are designed to suit people of all shapes and sizes and keep them safe.

4.10 Inclusive vehicle package and architecture- Making sure that decisions about vehicle architecture and packaging, made at the beginning of the design process meet the needs of excluded groups e.g. the height of the floor is made as low as possible to enable level boarding for wheelchair users.

Information and Interfaces

The Information and Interfaces area considers all of the ways that people may access information and interact with the SAV service through controls, digital interfaces, written information, and other modes of displaying information.

The main excluded groups that may be affected by non-inclusive design in this area are visually and hearing impaired people who may have difficulties if information is not presented with both auditory and visual means (Fürst and Vogelauer, 2012). People may also be excluded within this area if the information is not available in a language they understand (Schachter and Liu, 2005). Older people may be affected by lack of access to a smartphone and lower technology proficiency (Centre for Ageing Better, 2019) and unbanked passengers may be excluded due to a reliance on contactless payments (Brakewood and Kocur, 2013).

As well as issues of inclusion with regard to using digital information and interfaces, there are opportunities, provided by these services, that may help to meet other needs of excluded groups. Booking and planning interfaces, for example, may provide opportunities for priority seating to be booked which ensures disabled people have a guaranteed seat.

Although much journey information for SAVs may be provided through digital means, there will still be a need for non-digital information for purposes such as signage, wayfinding, and locating different vehicle functions. Non-digital information presents certain benefits to visually impaired people as it may be presented in a tactile way through braille and tactile flooring surfaces. This level of tactile information is not usually available in digital transport-based information and interfaces.

The following criteria relate to the design of SAV information and interfaces:

5.1 Publicly available booking and planning interfaces- Providing publicly accessible interfaces for those who don’t have access to a smartphone or another device.

5.2 Inclusive booking and planning app- Making sure that app interfaces are useable by all groups who may want to use them.

5.3 Inclusive on-board journey information- Ensuring that all information given during the journey is available in accessible formats.

5.4 Inclusive web-based information- Providing for those with access to the web but who are less likely to use a smartphone and ensuring that these interfaces are accessible.

5.5 Lo-tech alternatives to digital interfaces- Allowing for alternatives to contactless payment and less reliance on digital interfaces to use the service.

5.6 Inclusive, clear signage and wayfinding- Ensuring that all groups are able to navigate within and outside the vehicle and easily identify features that they need to use.

5.7 Inclusive permanent information- Making sure that information that is permanently situated in the vehicle or infrastructure is provided in accessible formats including high contrast, large print, audio, and tactile formats.

Inherent SAV qualities

While there is a lot of work to be done to ensure that SAVs are designed to meet the needs of excluded users, some points of exclusion from the literature may already be addressed by certain inherent qualities of SAVs.

6.1 Door-to-door service- Door-to-door operation of SAVs benefits a number of groups who currently experience barriers within the built environment when walking to and from the vehicle, by providing them with a service that meets them at their door. This door-to-door service could be improved through provision of designated SAV spaces near disabled peoples' homes and key locations as well as the provision of dedicated SAV lanes.

6.2 Driverless- While there may be a number of benefits for excluded groups to having a driver in the vehicle, many groups experience exclusion as a result of the behaviour and attitudes of the driver, including racism, poor driving and lack of disability awareness (Fürst and Vogelauer, 2012; Risser, Iwarsson and Ståhl, 2012; Ge *et al.*, 2016). Removing the driver and automating this role may result in fewer driver-related exclusions, although, as mentioned above, SAV design needs to replace the positive roles of the driver that might be absent.

6.3 Connected- The connected aspect of SAVs enables them to better respond to demand and navigate more efficiently. Although transport efficiency is a universal desire, it was mentioned regularly as an excluding factor in the literature as a lack of efficiency often characterises the experiences of excluded groups who are less likely to benefit from the efficiency of private vehicle use. SAVs may present a level of efficiency for excluded groups that is not currently available in the transport services that are available to them.

Conclusion and recommendations for further research

This paper has presented how existing issues of transport exclusion gathered from a range of literature have been used to develop several inclusive SAV design criteria, which fit into 5 areas of inclusive SAV design intervention: *Service, Infrastructure, SAV Operation, Vehicle Design, and Information and Interfaces*. These criteria may be used by SAV designers and other stakeholders as a starting point to develop more inclusive SAVs and SAV services.

While exploring existing transport exclusion allows for many insights into how excluded groups experience transport and does enable discussions around how future mobility could be designed, further research should explore how members of these groups envisage that new barriers might arise from the introduction of SAVs. Further research should also explore these criteria in more detail alongside members of the full range of transport excluded groups, through participatory design or similar participatory research methods.

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People Moving through Space

Towards a comprehensive framework to decode spatial exclusion

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Mainstream literature on socio-spatial exclusion is varied in its observations about different types and layers of exclusions, which include, but are not limited to access, socio-political exclusion, gendered exclusion, exclusions on mobility etc. In spatial design pedagogy there is a need for an approach that introduces different dimensions of spatial exclusion to learners in a cohesive manner. Especially among undergraduate learners, there is a need for this understanding to focus more on the scale of buildings and individuals accessing spaces.
This paper proposes a comprehensive pedagogic framework to decode spatial exclusion by postulating that it occurs as "people move through space". Therefore, it is impacted by –

- The people moving through the space: the types of identities that people possess with respect to the physical bodies they occupy and associated identities (physical abilities, skin colour etc.), their metaphysical experiences (cognition, emotions etc.) and their social identities (how their physical & metaphysical dimensions are received in the society).
- The acts of "moving through" expressed as accessibility and mobility, which include safety, speed etc.
- The material properties of the physical space which includes the materials used, dimensions, distances etc.
- Additionally, the interaction of people with others in space - as this creates socio-political dynamics.

The paper presents the proposed framework in relation to different mainstream texts. It is examined and demonstrated through masters' student projects which feature case studies from India, Brazil and Jordan. Application of the framework in a studio setting is also demonstrated.

Keywords: *spatial exclusion; architecture; metaphysical exclusion; spatial inclusion*

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Introduction & Scope

Discussions and initiatives around spatial justice and inclusion have been on the rise in academia in the recent past (Philippopoulos-Mihalopoulos, 2015). However, mainstream literature around exclusion in physical spaces is yet to witness the rise of a holistic theory of spatial inclusion and exclusion. This paper proposes a pedagogic framework that can initiate a holistic theoretical approach towards decoding spatial exclusion in the spatial design pedagogic space (architecture, urban design, planning etc.). The study of exclusion provides a crucial foundational understanding of the existing conditions that need to be addressed in order to design for spatial inclusion.

The scope of the framework is to introduce concepts of spatial exclusion to senior Undergraduate students (Year 2 and above) or junior Postgraduate students. Therefore, the focus shall be on the scale of individual urban buildings and people accessing them. The scope is limited to experiences of exclusion within built space.

Literature, Relevance and Methodology

Examining Existing Literature

Six lists of literature on socio-spatial exclusion, relevant to pedagogy, were reviewed including postgraduate course syllabi (Akkar, 2017) (Carmin, 2004), recommended reading lists for students by universities (University of Toronto, n.d.) (*Spatial Justice Studio | Center for Design Innovation*, 2022) (The Spatial Justice Network, n.d.) and two issues of Justice Spatiale, Spatial Justice (Dufaux et al., 2009) (Froment-Meurice and Hancock, 2021).

This review revealed the following areas of discussion around experiences of spatial exclusion:

- People and their relationship to socio-spatial exclusion, more specifically, bodily & socio-political Identities, human emotional/cognitive experiences e.g. (Rothstein, 2017)
- Space and policy as tools in generating diagrams of power, e.g. (Lee Jr., 2020) (Foucault and Sheridan, 1995)
- Space as a causative agent or catalyst for socio-spatial exclusion, e.g. (Mortice, n.d.)
- Discussions on accessibility and mobility such as relationships between mobility & gender e.g. (Roy, 2003), barrier-free design of space e.g. (Steinfeld and Maisel, 2012), safety of access and neighborhoods e.g. (Morelle, Tadié and Hancock, 2011) etc.
- Social exclusion and community action in and around space. e.g. (Natarajan, 2019)

To validate these findings, a literature review was conducted through meta-analysis (Davis et al., 2014) in the Taylor & Francis database as depicted in figure 1. The abstracts of relevant articles in the search results were perused and qualitatively analysed to determine which areas of spatial inclusion or exclusion were addressed in the article. All the abstracts analysed indicated that the articles contained information or analysis pertaining to one or more areas of spatial exclusion described in this section (Figure 1).

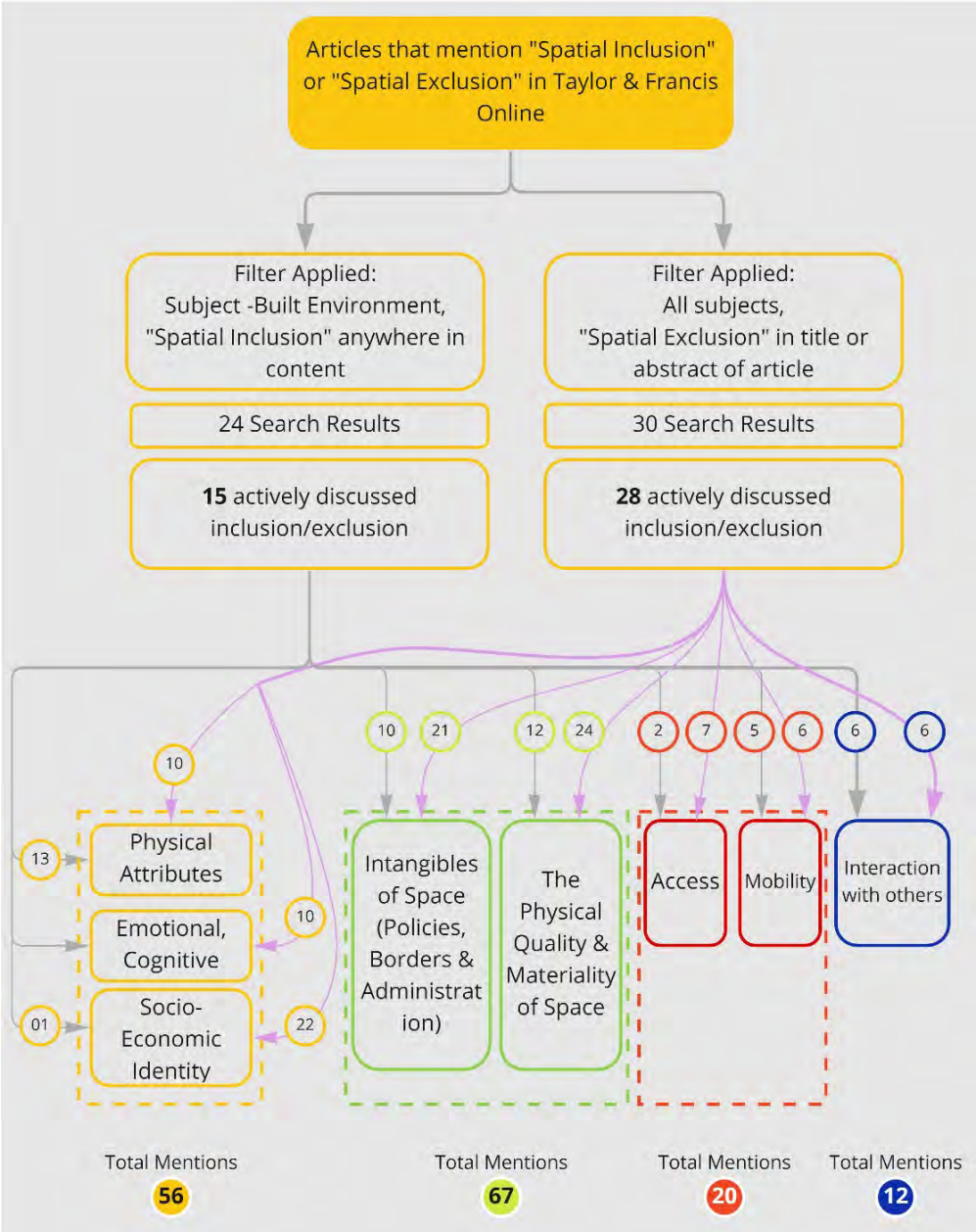

Figure 1. The results of literature review. Source: Author

Why This Topic Merits Discussion

Spatial design education requires context-specific or site-specific understandings. While contemporary literature on inclusion and exclusion delivers rich intensive content on a particular theme of inclusion studies such as urban mobility, gendered inclusion etc., there is very little public literature on spatial inclusion that discusses a holistic framework for the study of a specific site, building or public space. In design-oriented undergraduate studios which do not intensively delve into theory of inclusion, there is a need for methods or tools that can be applied directly to the design process. Also, discussions that go beyond barrier free environments must be actively encouraged and woven into the design process and undergraduate curriculum.

Methodology

This paper introduces a framework encapsulated within the phrase “People Moving Through Space” as a lens or a rational construction to explain the experience of socio-spatial exclusions of individuals in a given built environment. This is done in order “to develop…explanations, and predictions that hold true in all cases of a behaviour under study” (Groat & Wang, 2001).

The paper employs a descriptive case study methodology (Yin, 2018) to demonstrate the validity and applications of the framework through discussions on masters’ student projects based on real sites in India, Jordan and Brazil. Concept mapping (Santiago, 2011) is a data visualisation technique used to depict hierarchies between different components and to establish relationships between them by use of signifiers (such as arrows or lines). As evidenced in Figure 10 and Figure 11 concept mapping is employed to create maps that visually replicate the hierarchies of the proposed framework (Figure 5).

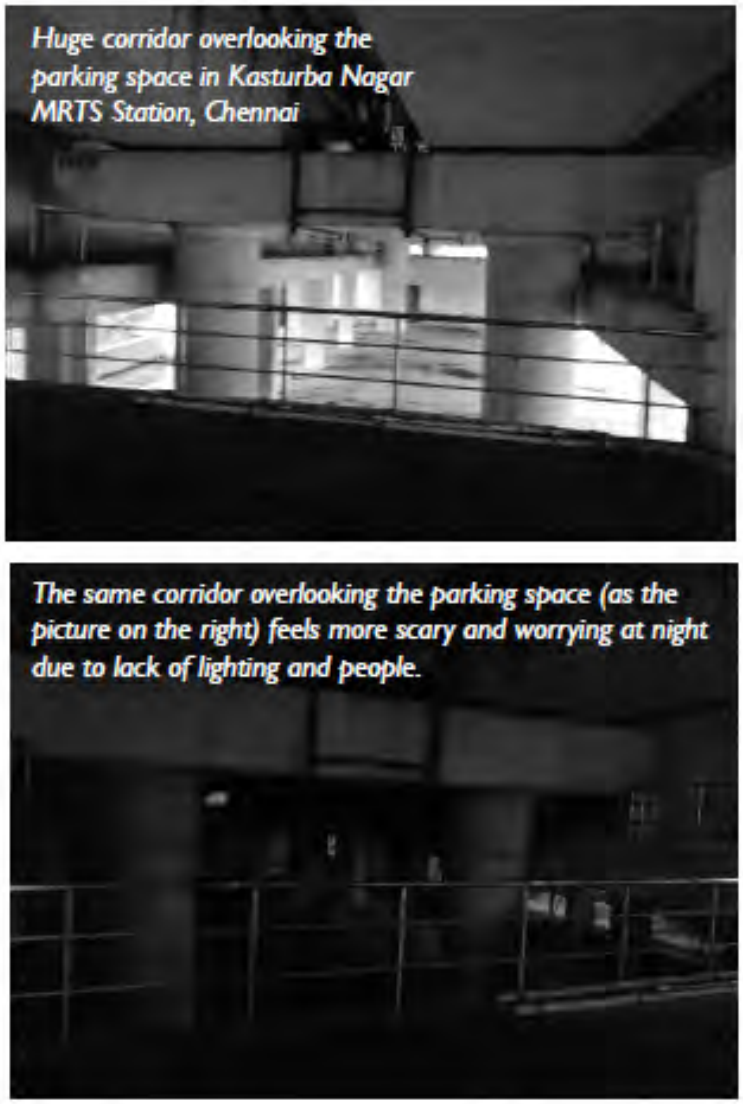

Figure 2. Comparison of two images of the same space at day and night). Source: (Srinivasan, 2017)

Properties of Exclusion

Exclusion as a spectrum

The dictionary definition of excluding is the prevention or restriction of entrance ("exclude", n.d.). While this definition makes exclusion seem absolute, the experience of exclusion often occurs on a continuum (Burchardt, Le Grand and Piachaud, 2002). For example, Weisman (1994) discusses women's exclusion from city streets by patriarchy. She is not referring to an absolute exclusion i.e. a law that prohibits women from occupying the streets. She is referring to a much more complex form of exclusion where women are socially taught to avoid streets that have a high male presence and instances of gang violence. There is a social implication which is encoded as a cognitive message in the minds of women that certain streets are "unsafe".

Exclusion as a Temporal phenomenon:

Nawratek and Nawratek (2015) discuss how radical inclusivity can perhaps only happen at certain frozen moments of time. This implies that states of inclusion and thus, exclusion change with time. Figure 2 shows two pictures of the same space in a train station in Chennai (India). The appears benign during the day but at night, many women traversing through the same space found it unwelcoming and scary (Srinivasan, 2017).

Components of the Framework

The four critical areas of examination required to understand exclusion in an existing built space (Section 2) shall become the components of the framework.

Physical, Metaphysical & Identity: Mind, Body & Society

1) The Physical Body:

As experiences of exclusion happen through the physical body it becomes crucial in understanding exclusion. Discussion around the body dimension of exclusion encompasses many aspects such as body positivity, limbic (dis)abilities, sensory (dis)abilities and neurodiversity. Anthropometric architectural standards[1] which are prescribed to Undergraduate architecture students, have garnered criticism (Masson, Hignett and Gyi, 2015) (Steinfeld, Lenker and Paquet, 2002) (Hobson and Molenbroek, 1990). The reason for this critique is the lack of sufficient information and flexibility in these standards to truly represent and match the diversity in body types, dimensions, physical abilities, neuro-divergence and needs of people. For example, Figure 3 from Neufert's Standards (Neufert et al., 2002) depicts a set of body dimensions as "normal" and does not take into account different body dimensions such as weight, height or limbic abilities.

[1] A set of standard dimensions (based on human body dimensions) for space needed for activities and furniture usually occurring in the form of books prescribed to undergraduate students of spatial design.

2) The Metaphysical: Emotional, Cognition and Experiential Dimensions:

Figure 4, depicts a visualisation of the cognitive map and the emotions of a young woman while moving through a public train station in Chennai, India at night (Srinivasan, 2017). As she traverses the space, she has every legal right to move freely through the station once she has bought a ticket. However, her emotional experience is of fear and anxiety. Also, if she were to move through this space during the day or when the station is more populated, her anxiety wouldn't be as severe. Closely linked to socio-political and bodily identity, is the emotional and cognitive experience of space. Each individual experiences space and perceives security differently (Minton, 2012). Based on past experiences and their social identities, people develop cognitive understandings and maps of different spaces in order to navigate them safely and efficiently (Weisman, 1992).

3) Socio-Economic and Socio-Political Identities:

In addition to physical attributes, people are associated or self-associate with identities that are constructed in the socio-political and socio-economic sphere which include but are not limited to gender, race, queerness, class, caste, literacy, immigration status, citizenship, nationality etc. (Cerulo, 1997). These identities may also be interlinked to physical attributes. For example, while skin colour by itself may be a physical attribute, in a socio-political sphere it can be interpreted as racial identity or as a method of "othering" based on political positioning, and cultural heritage (Jablonski, 2020). Similarly, neighbourhood segregation based on household income has been observed (Browning et al., 2017). The difference created by this economic aspect of income can manifest as a part of one's socio-economic identity.

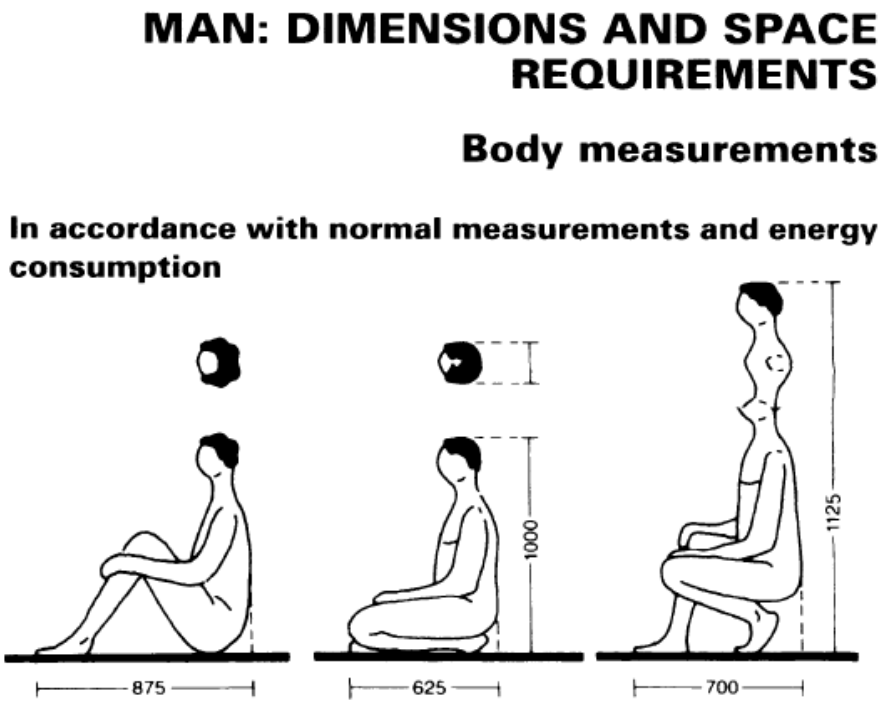

Figure 3. Image Source: (Neufert et al., 2002)

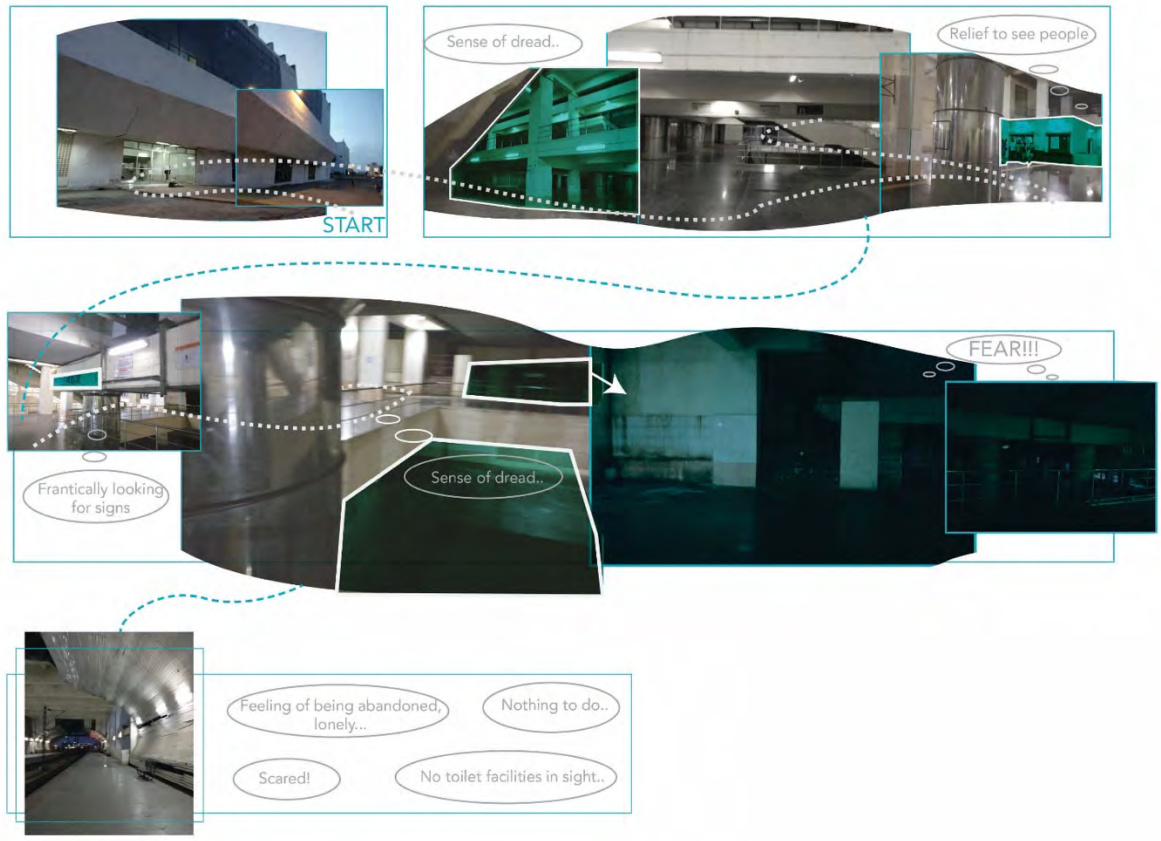

Figure 4. Cognitive map of young woman at night in a train station. Source: (Srinivasan, 2017)

Space as an Instrument, Catalyst or Deterrent

1) Physical Space:

Physical space can be used as an instrument to create segregation and “defensible spaces” (Newman, 1978). Exclusions can also occur as the unintentional consequence of spatial design. B.Schindler (2015) discusses how architecture can be used as a regulatory mechanism to socially segregate through built forms. Bannert and Elnokaly (2013) discuss the unintended exclusion of the disabled in the city of Lincoln due to its design features such as steep inclines. Literature reveals four qualities of tangible physical space, which will be hereafter referred to as “material realities” of space, that can be instrumental in the generation of exclusions:

- Distances and dimensions of space,
- Barriers and lack of access infrastructure,
- The materials that the space is made of,
- Sensorial experiences created by spaces i.e. smell, noise etc.

2) Intangible Spatial Conditions:

Most physical spaces are governed by intangible conditions such as administrative policies, political conditions, laws or border conditions. Their presence is witnessed in the form of infrastructure (for example, biometric entry door locks) or through a labour force (like policing). Like material realities, these intangible conditions can be

used to generate exclusions. Conversely, space can also be used to deter exclusion through material realities and through intangible conditions.

Mobility and Access

The exclusion occurring during the act of "moving through" a space consists of two components – the access to the destination (or mode of movement) and the conditions of mobility.

1) Access: Exclusion by its very definition is the lack of access. Often, measurements and understandings of exclusion are used synonymously with "lack of accessibility" (Akkar Ercan, 2004) (Steinfeld and Maisel, 2014). Therefore, we can conclude that lack of accessibility is *the consequence or the end product* in the process of exclusion.

Physical Access: Universal design, barrier-free environments and standard dimensions for providing access to the differently abled in spatial infrastructure have constantly been featured in discussions of spatial exclusion and inclusion (Steinfeld and Maisel, 2014).

Access to Information: Various kinds of information in the form of physical features (e.g. signage) or digital tools (e.g. google maps) are required to navigate and access spaces. Access to this information can be hindered by lack of infrastructure that conveys information or by information infrastructure not catering to everyone. For example, lack of audio or tactile signage can hinder wayfinding for people with vision impairments.

2) Mobility: Literature points to different dimensions of mobility related exclusions such as urban mobility (Tonkiss, 2015), gendered mobility (Jarvis, Kantor and Cloke, 2009), last mile connectivity (Marfatia, 2019) etc. Exclusions can be especially exacerbated for some individuals during the process of "moving through". For example, individuals of advanced age or those with limbic disabilities are particularly affected by lack of supporting mobility infrastructure. Tournier and Vidovićová (2021) highlight the mobility exclusions faced by individuals in advanced age groups and how this shapes their life experiences.

Review of mobility infrastructure further highlights that exclusion in this domain is often measured through mobility i.e. *mobility is a visible impact that articulates exclusion*.

3) Safety: Considerations of safe access and safety in mobility are key to create inclusive environments. A variety of literature, projects and initiatives discuss lack of safety as an important measure of exclusion and its close relationship to gender & identity (*Safetipin, Creating Safe Public Spaces for Women*, n.d.).

Socio-politics in Space: Interacting with One Another

As illustrated by Jacobs (1993) in her seminal text, the presence of others in a space can create natural surveillance and a sense of safety which this paper has previously established is an important measure of exclusion. Additionally, activities such as street vending and resultant interactions can promote a greater sense of belonging and thus, safety. They also have the potential to generate community networks and a sense of public ownership which can be important deterrents of exclusion. Conversely, as depicted in fig 2., a lack of public presence can alienate and heighten anxiety & lack of safety.

The Interrelationships Between the Four Components

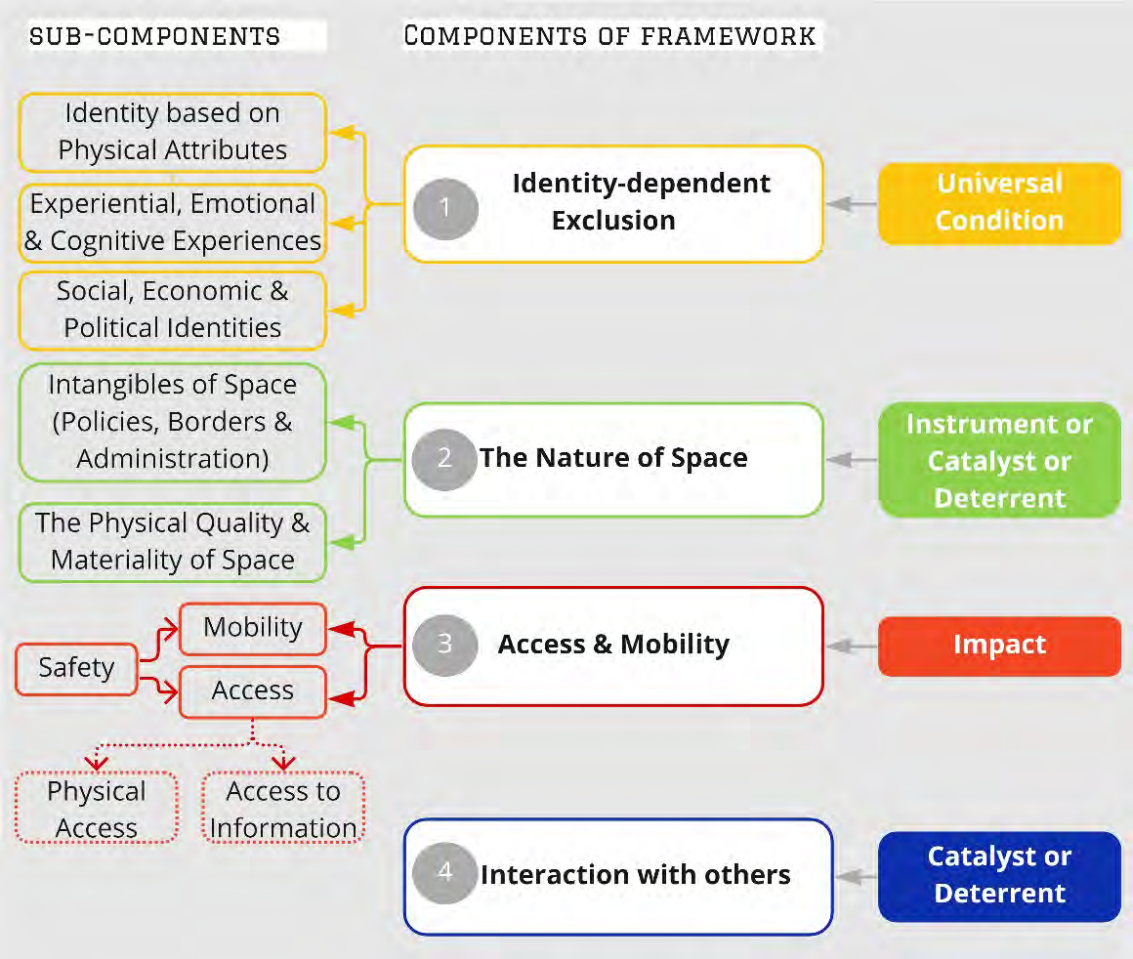

Figure 5. Concept mapping of the framework, Source: Author

The experience of socio-spatial exclusion can be articulated through four concepts described previously in this section.:

- Identity of the individual, as *a condition for exclusion* (people)
- Accessibility and Mobility as *a measure or impact of exclusion* (moving through)
- Space as *an instrument or catalyst of exclusion* (space)
- Interactions with other people in space or the lack thereof as catalysts or deterrents of exclusion.

Thus, exclusion can be understood using the framework of “people moving through space”.

People Moving Through Space: Demonstrating The Framework Using Case Studies

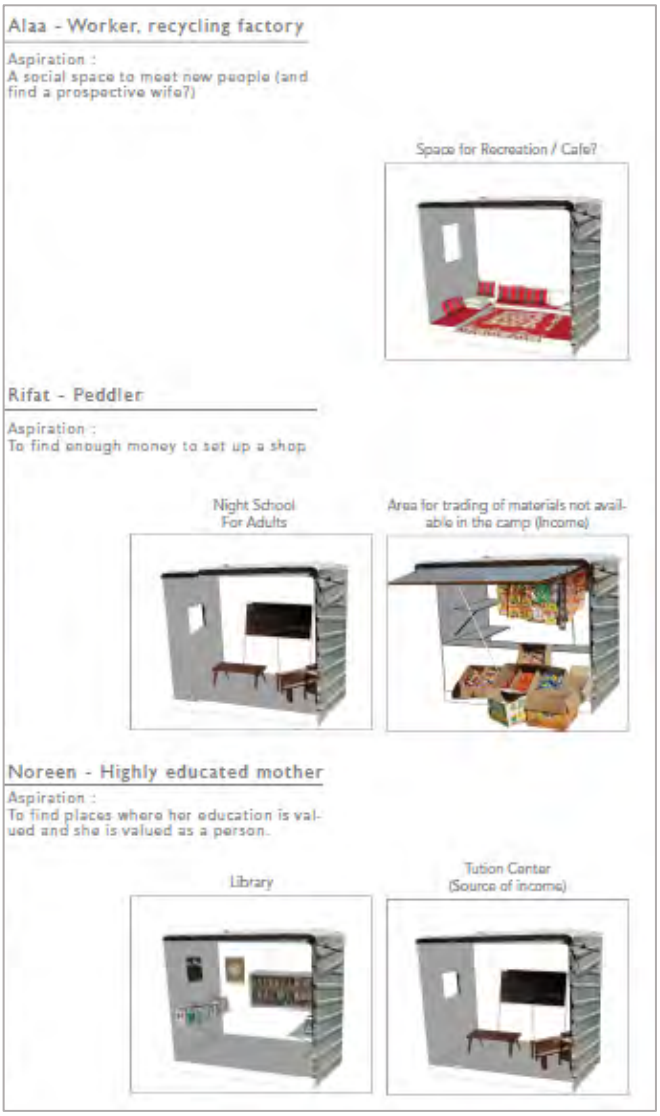

Figure 6. Different material infrastructure required for different actors to to be included in the larger economy of the camp, Image Source: (Srinivasan, Zhang, Li, Pang, 2017)

Identity & Space:

The experiences of inclusion & exclusion of each individual is deeply intertwined with their identity. Temkin (2001) argues that the focus of studies on inequalities must focus on individuals as opposed to groups (based on racial identity, gender identity etc.). Figure 6 depicts the example of how three individuals[2] residing in Zaatri refugee camp, Jordan while sharing the same larger geographic space of

[2] In the project, these three individuals were fictional identities constructed based on interviews conducted in the refugee camp. The fictional identities were constructed to preserve the anonymity of those interviewed. Ethical approval to use interview data for design was obtained during the course of the academic project. Scenario games (Binet, Bunschoten and CHORA, 2001) were used as the methodology to develop narratives about these three fictional individuals.

residence, the refugee camp, and belonging to the same larger socio-political group could have different qualifications and competencies. They would therefore be in need of different types of material infrastructure & spaces in the camp to be included in the economy of the camp and the neighbouring city (Amman). Therefore, this implies that:

- the type of exclusion is dependent on the individual's identity and
- the physical space and material required to alleviate exclusion is dependent on the same.

Access & Space:

Figure 7 shows an analysis of the changes in material realities ("Positive Impact") and potential for further change ("Need for Development") created by the UN Habitat finalist project at Audi Unaio at Curitiba, Brazil. In this redevelopment project, creating material realities that improved access to the city (urban mobility) and to basic services was one of the primary instruments used to eradicate social exclusion.

For example, before the redevelopment, situated in the primary floodplain, the favelas (informal houses) and the unpaved streets in Audi Uniao were constantly damaged due to recurring floods. The situation was worsened by the lack of a planned drainage system. The narrow roads also made it difficult for buses or larger vehicles to enter the shantytown causing decreased urban mobility. In summers, due to unpaved roads, the air in the neighbourhood was constantly dusty risking the health of the inhabitants (Srinivasan, Kouri, Lagunes Trejo and Gamez, 2017).

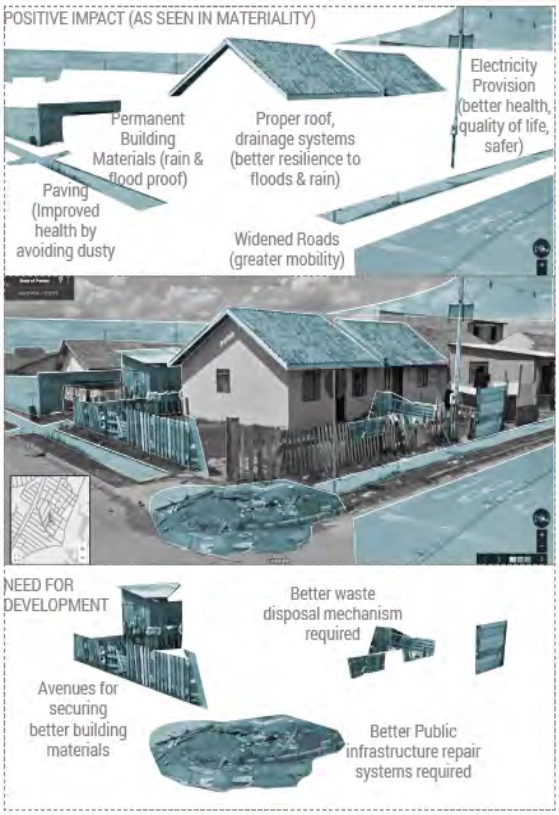

Figure 7. The *different material infrastructure that helped create inclusion (positive impact) in Audi Unaio and the material infrastructure that can be improved to make the space more inclusive, Source: (Srinivasan, Kouri, Lagunes Trejo, Gamez, 2017)*

The re-development initiative was not limited to creating housing but also facilitated road widening and paving of the streets. Simply paving the crucial areas of the shantytown did much to the development of the community. The paving prevented dust clouds from forming in the streets and promoted health & well-being. Formalised roads paved in asphalt, creates opportunity for larger vehicles to enter the shantytown and move through it improving its allowance for urban mobility. Wider roads also created the possibility for larger public transport (Srinivasan, Kouri, Lagunes Trejo and Gamez, 2017). This clearly illustrates the interdependency of the quality of space and access as cause/instrument and effect/impact respectively.

Figure 8. Visualisation of tactical intervention proposed to convert a dark pockets of space at night into a space that creates opportunities for natural surveillance, Source: (Srinivasan, 2017)

People Moving Through Space

As previously discussed through Figures 2 and 4, young women were excluded in Kasturba Nagar MRTS station, Chennai at night. Further, the quality of physical space which does not allow visibility from other parts of the station and the darkness in this space catalysed the exclusion. A simple solution was proposed in the design thesis that studied this exclusion as shown in Figure 8. Lighting and a temporary public exhibition space introduced in the dark pocket can boost natural surveillance from exhibition visitors, encourage regular maintenance of lighting and thereby promote a sense of safety.

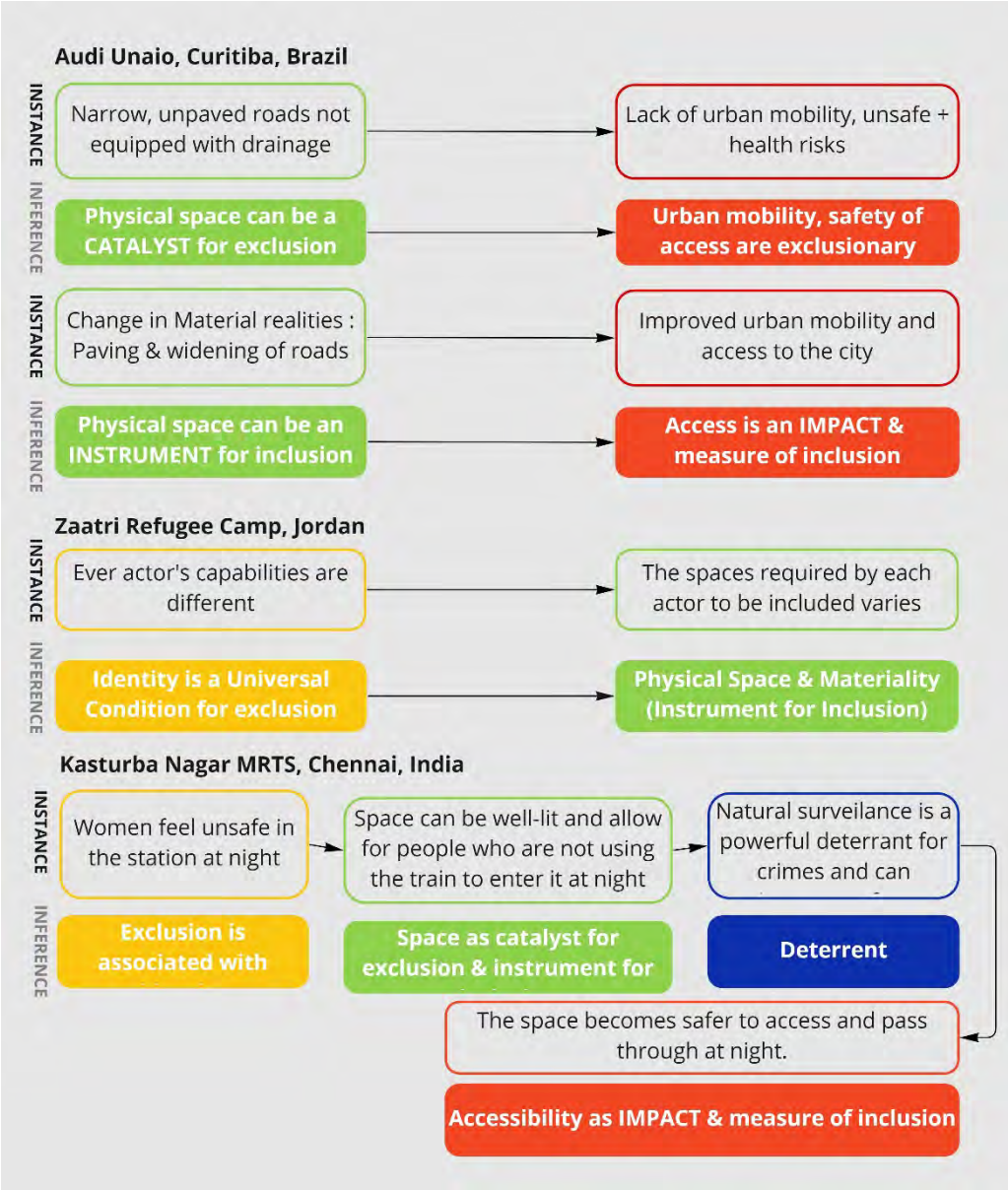

Figure 9. The instances and inferences from the three case studies to demonstrate the validity of the framework proposed in this paper, Source: Author

Application in Design Studios

Understanding Citizen Participation

While participatory activities and co-design aren't within the scope of the spatial experience of exclusion, the degree of involvement of citizens in spatial decision making can, to a great degree, affect the experience of exclusion or inclusion. The framework can be used as a skeletal structure to generate questions about the effectiveness of participative strategies when performing case studies of best practices (Figure 10). These questions can be used to generate discussions on where the design processes followed feature on the citizen ladder of participation (Arnstein, 1969).

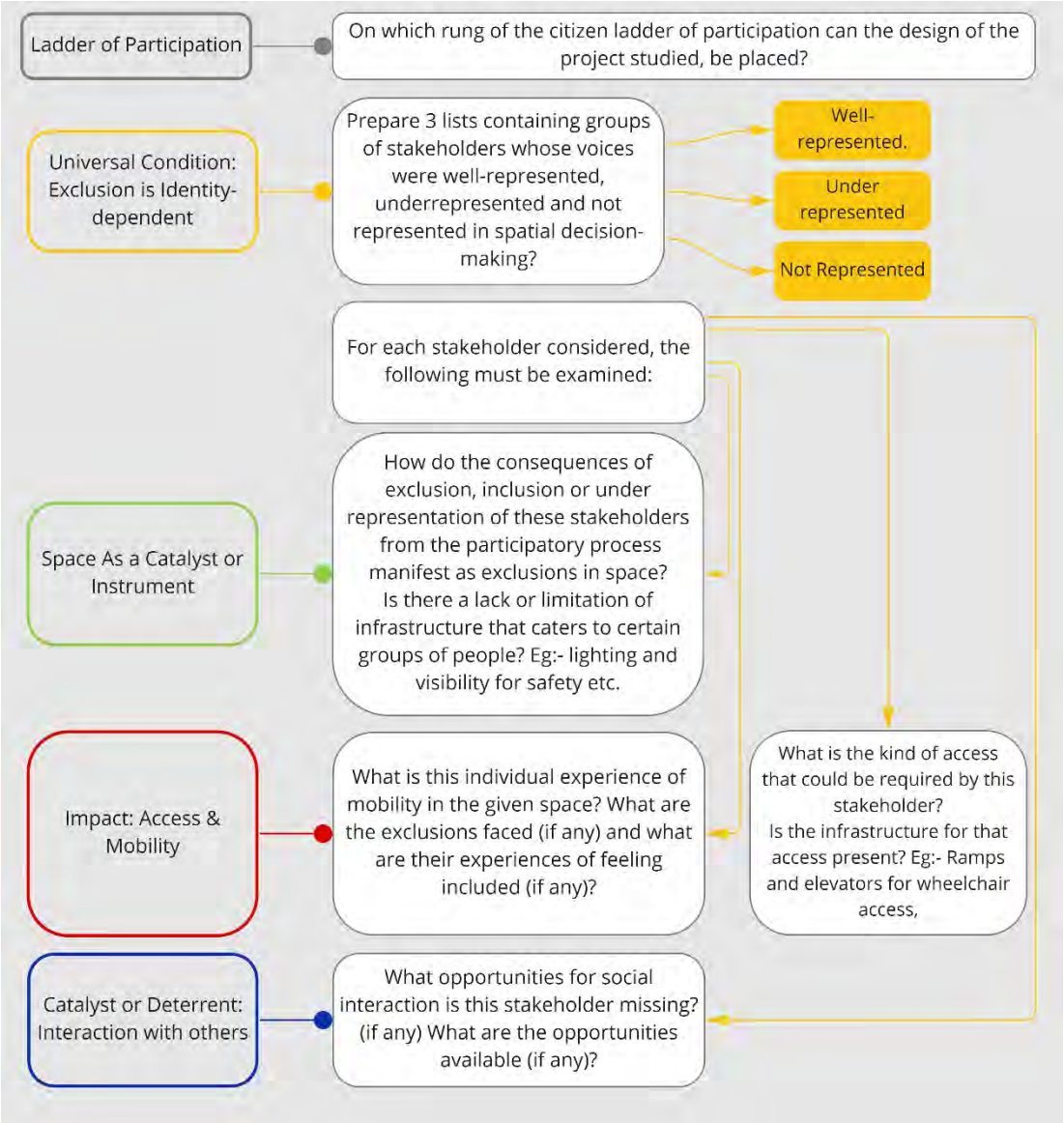

Figure 10. A concept mapping of a series of questions generated to understand the effectiveness of co-design and participative strategies used in design processes based on the framework proposed in this paper; Source: Author

Enhancement of the spatial design process

Integrating understandings of spatial exclusion under one holistic framework has the potential to be incorporated in the following steps of the spatial design pedagogy and practice:

a) Introductory Theoretical Framework: It can serve as a comprehensive starting point and introduction to the typologies of spatial exclusion in a simple manner.

b) Critical case studies - to analyse an existing project or built environment critically and help identify the conditions, instruments and impact for inclusion or exclusion. Figure 11 illustrates a uniquely interconnected series of question prompts generated based on the framework proposed which can be directly used in the studio space to help students critically examine case studies. Alternatively, this could also be used as a reflective framework at the end of the design process where the students use the prompts to evaluate their design output for exclusion & inclusion.

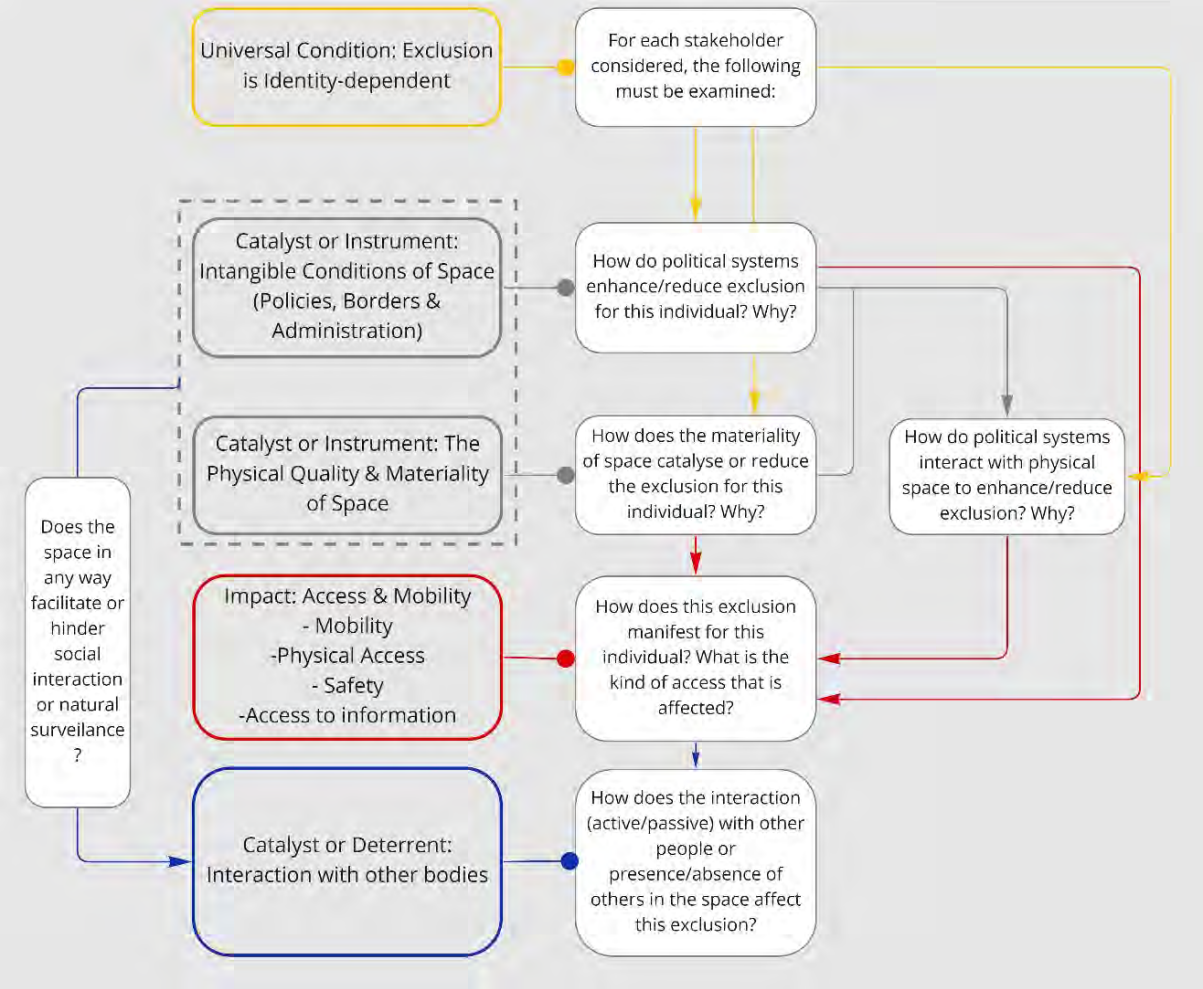

Figure 11 depicts a concept mapping of a series of questions generated based on the framework proposed in this paper; Source: Author

c) Ideation: The framework possesses the potential to generate tools and methods similar to the one depicted in Figure 11, that focus on design ideation responding to exclusion.

Therefore, incorporating this framework within the studio can make the design process more responsive to different types of spatial exclusion and facilitate active integration of theories of inclusion in the design process.

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Academic Posters

Abstracts

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Beyond Ageing Stereotypes

Imagery & iconography

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Ageism is a relatively modern construct arising from significant increases in life expectancy. For example, Stone Age representations of older people simply noted differences in hair colour. Frailty stereotypes are unrepresentative, because the majority of older people have diverse functional capacity. Nonetheless, ageism within the media is widespread, with older people, even in contemporary dramas, often limited to stereotypes of snowy-haired invisible grandparents or homeless people. Similarly, prevalent icons of older people often utilise stereotypes of physical frailty. A notable example is the 1981 United Kingdom road sign for slower, frail people crossing the road, which is designed to notify drivers to reduce vehicle speed. It depicts a frailty narrative that has become the archetype for iconography of older people. Such stereotypes lead to the design of digital technologies focusing on healthcare, rather than desires and aspirations. So, we suggest an alternative iconography for older people, moving beyond stereotypical physical frailty, and approaches to addressing ageism stereotypes in wider society through popular media. We conclude by moving beyond ageing stereotypes, counterbalancing the mostly negative ones to affect changes in perceptions of popular culture, which is critical not only for the older people of today, but also our future selves.

Keywords: *ageing; stereotypes; icon; media*

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Determining the Social Value of Design

Ageing in place

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Determining the social value of design: ageing in place as part of a vibrant urban community that includes later living, specialist disability accommodation, commercial tenancy, short stay accommodation (platinum level accessibility) a function centre and social/welfare/human services delivery.

Using an innovative Social Value Framework developed for this case study, this project will investigate whether the social benefit of building mixed-use vertical communities can be quantified with specific benefit for later living, including end of life stages. The project will establish the multi-dimensional impacts of such a development in practice, giving a voice to the consumer whose desire for an urban presence in a diverse and inclusive community has been consistently underrepresented in Australia.

The project uses citizen science for real time auditing of the built environment by residents and users; smart technologies for environmental and behavioural monitoring; and data analytics and design automation for spatial analysis of building use. The results will inform new models of sustainable high-rise, mixed-use buildings providing evidence for the international application of diverse, vertical communities that value the inclusion of community from across the life stages.

Keywords: *ageing in place; social value; later living in mixed use developments; building community*

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Service Design Proposal for a Holistic Care Ecosystem to Manage Polycystic Ovary Syndrome

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frog design

Polycystic Ovary Syndrome (PCOS) is a chronic endocrine condition and is one of the leading causes of female infertility. It is incurable and linked to long-term health risks but can be controlled and managed well when treated holistically. Since there is no standardised treatment and management strategy followed, the process of finding long-term relief is complex and tiring. This poster first investigates the journey of patients with this condition, their unmet needs and problems while receiving care, and existing treatment protocols for managing the condition. Then, the gaps in the ecosystem are understood and opportunity areas to alleviate the same are derived. Finally, a service design concept for a holistic PCOS care ecosystem that offers comprehensive, personalised long-term support to help patients manage the condition effectively and thus improve their quality of life is proposed.

Keywords: *service design; PCOS; care ecosystem; management*

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Understanding Gender Bias in Pain Assessment and Designing for Equitable Care Delivery

Enabling equitable pain management

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Historically being inclined towards the average white male, the healthcare systems and processes are not equitable, and pain management follows suit. Women's pain has been disregarded, tagged as hysteria and misattributed to psychological reasons for a long time. With lesser research on the female body, women being seen as a weaker and emotion-driven gender, and a distorted understanding of sex and gender may lead to delayed and improper pain management for women. The study captures how gender norms and biases affect the actions and behaviours of the primary actors (patients and healthcare professionals (HCPs) involved in the pain management process. It also highlights the downstream effect on the treatment delivered. Service design approach, supported by qualitative research methods was used and the findings are presented as a perception-communication-assessment model, focusing on the primary actors and their interaction. Solutions explored in the work aim at changing the actions and decisions of the actors to enable equitable care delivery in acute care settings. Aiming at Equity through Empathy, the outcome of the work is a design brief for a pre-consultation tool to facilitate patients' understanding of their pain and clearer communication with HCP thus bringing more trust to the process.

Keywords: *gender bias; pain assessment; equitable care delivery; service design*

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Design and Meaning Making through Collages and Language Diversity in North Central Florida

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North Central Florida is not usually perceived to be as linguistically diverse as other parts of the state such as Miami or Orlando. However, there is a significant population of migrants who speak languages other than English. In contexts of global migration, language barriers can increase when language diversity is not properly recognized, making it difficult for those not speaking the predominant language of a place to actively participate and feel included in their communities.

Through a set of postcards with collages, the author intends to raise awareness of the linguistic diversity in North Central Florida by visualizing the meanings people assign to their languages and the obstacles caused by language barriers. The collages were designed based on interviews with multilingual community members. Exploring and negotiating the images and their meanings with participants brought to light how other aspects of their identities such as race and religion are connected to language.

The results show that the collages, as a visual language, have the potential to decentralize the weight of spoken and written languages. The collages can work as inclusive platforms to make sense of information and facilitate the participation of multilingual individuals in contexts where there are language barriers.

Keywords: *collages; language justice, language diversity*

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Museums for All? Project Svaritha: Designing Empathetic Museum Experiences for Socio-Economically Disadvantaged Children

A case study from the Indian Music Experience Museum

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Children from socio-economically disadvantaged backgrounds (CfSDB) often lack access to cultural institutions like museums. An inclusive musical immersion experience supporting holistic developmental learning, Project Svaritha, was designed by the Indian Music Experience Museum in partnership with ReReeti Foundation for 500 such children. Following a best-practice review, using a participatory action methodological approach, data was gathered from 125 children, 20 caregivers, & 8 child-rights advocacy professionals through bilingual surveys, focus groups and interviews. The tour, which over 500 children have now experienced, was designed around three learning outcomes. Additionally, sector best practices were identified and used. Impact evaluation demonstrates positive influence on children's sense of belonging, clear learning outcomes, and many asking to deepen engagement. This child-led research provides unique insight into children's lives and a blueprint for museum engagement programmes with under-represented audiences. Universal design principles can create impact, and conversely, exclusivity can be an inclusive practice.

Keywords: *social impact of museums; exclusivity=inclusion; child-led participatory; research accessible design*

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Computational Design Experiment for Older Adult's Footwear

Field-driven approach and product design applications

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The purpose of the study is to build tailor-made footwear soles for older adults through field-driven design and technology to satisfy their unmet needs and respond to the two research questions: 1. How to translate people's feet pressure data to shape the three-dimensional model of footwear soles to generate customized products? 2. How has the field-driven design approach transformed the roles and responsibilities of product designers and thus shaped human-centered design (HCD)?

One pervasive effect of aging is people's feet undergo a significant loss of cutaneous touch and pressure sensation. Their feet gradually become deformed and asymmetric depending on health, lifestyle, and walking postures. Mobility is a key factor to measure their life independence and we think footwear soles are the product most directly linked to mobility.

Field-driven design is a computationally lightweight process that is applied to three-dimensional objects through a single mathematical formula reinterpreting a solid body. It has made the process intuitive to precisely control models, simulate results efficiently and effectively. This study showed how we translated feet pressure data to rebuild comfortable, safe, and customized footwear soles for older adults and discussed the future roles of designers and HCD impacted by field-driven design and technology.

Keywords: *computational design; field-driven design; footwear; aging*

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Exploring People's Behavior Through Tracking Assistive Technologies

Ultra-wideband wireless technology and applications

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The purpose of the research is to analyze the relationship between space and people's behavior in confined environment and how we translate people's trajectory data into meaningful information. This informs the designers to build a human-centered environment with and for users not only in physical space alone but also in physical space enhanced by services. We attached ultra-wideband (UWB) wireless radio technology operating between 3-10 GHz frequency, designed for accurate positioning (up to 10 centimeters precise), to conduct experiments by tracking people's behavior in a defined six zones. Then we captured people's time spent in each zone and the frequency of people entering each zone. Key learnings from the study: 1) translate people's behavioral data into business opportunities and 2) design needs to reconsider users' dignity and data privacy, helped us integrate UWB technology with space design. Our goal is to transform a space design process by deciphering people's behavioral data to reconsider how to deliver a space experience and build space models with and for people, catering to their desires and living conditions. A future research question is to disentangle the variances between users by the design of the space, vs. personal preferences and patterns of behavior. Note: Part of the experiment obtained approval from the MIT COUHES (Committee on the Use of Humans as Experimental Subjects).

Keywords: *human-centered design; behavior data; indoor positioning; ultra-wideband*

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Sensory Nourishment

Exploring inclusive design methods within fashion practices

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The sensations in our environments can be experienced at unbearable levels by people on the autism spectrum and other neurodivergent groups, in particular those with ADHD. Clothes are our most immediate environment, yet, dominant fashion design practices rarely consider the impact of the sensations they craft. Furthermore, clothes are conceived statically, which is at odds with the dynamic movements in everyday life.

My ongoing practice-based PhD research actively includes 12 participants with heightened sensory responses. Collaboratively we explore ways in which more conscious clothing design can improve their well-being. Whilst these participants have diverse sensory needs, they desire access to universal emotional experiences.

This poster introduces my use of wardrobe studies to examine the relationship between participants, their existing clothing and clothing aspirations. The poster presents the insights gathered thus far that focus on *kinaesthetic - tactile - sonic* sensory experiences. Preliminary studies had placed the focus of my design practice on material properties. However, insights gathered in the wardrobe studies have shifted the moving body to the forefront of my design process to explore how it crafts sensations when in dialogue with materials.

Keywords: *autism spectrum; ADHD; sensory processing; fashion design; inclusive design*

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Intersectional Design

Design as a tool for social equity

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Today, we recognise in law and corporate practice that we must address discrimination by race, gender, sex, and other identity indicators. The 'design industry' directly shapes people's lived experiences. However, surveys show that the field lacks diversity. A comparison of existing methodologies also suggests a lacking awareness and capability of critically engaging with social responsibility. As a result, design can contribute to paradigms of oppression and discrimination.

This study proposes participatory design methods enabling explicit consideration of end-users structural identities and pressures. Some of its key components include the radical inclusion of marginalised stakeholders or canvases for mapping oppressions based on the intersectional theory and analysis of power dynamics surrounding the design context.

The framework was co-designed in workshops with diverse stakeholders. We tested the process in an accelerated co-design case study, through semi-structured interviews and think-aloud testing with practising design experts.

The early framework effectively and productively included marginalised stakeholders in 'reimagining' a sexist tradition and achieved positive appraisal, good fidelity and practicable outcomes.

It also raised exciting questions about its applicability by other designers; transferability across different contexts; and commercial integration.

Keywords: *design theory; intersectionality; participatory design; design justice*

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Technology Futures Roadmap for the Longevity Economy

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The Longevity Economy was recently estimated to generate nearly £11 trillion of economic activity, and there is considerable interest in emerging digital technologies that would bring living 'longer' closer to living 'well'. While this promise is inspiring, older people are rarely consulted in development, and the Longevity Economy has an inherent duality, with the majority of older people having diverse functional capacity, and only a minority being disabled. Acknowledging this inherent duality leads to age-friendly design in the development of mainstream digital technologies, moving beyond medical products to aspirational age-inclusive design. However, this requires better understanding the relationship between emerging digital technologies and the future needs of older people in the Longevity Economy. We therefore considered Technology Futures, specifically age inclusivity through an enhancement model for the development of mainstream digital technologies. Therefore, offering enhancement for all ages with diverse functional capacity, inherently providing support for those with differing ability resulting from age or disability. We then identified emerging digital technologies significant to the inherent duality of the Longevity Economy. We present this in the form of a Technology Futures Roadmap, based upon Gartner's Hype Cycle, sharing our understanding of the emerging technology landscape for our future selves.

Keywords: *technology; digital; futures; roadmap*

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The Inclusive Approach

A methodology of the fundamental principles of inclusive design

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From the first use of the term inclusive design in 1994, to it's definition in 2005 by the British Standards Institute, society and daily lives have transformed. Although the original focus was on design for the elderly, inclusive design has broadened and is now used to consider wider diversities. This led to the question: What is inclusive design today? The aim was to identify the fundamental principles of inclusive design with the objective of creating a methodology to educate young Designers.

The project involved a research triangulation to address the aim and identify gaps in the current toolkits. This involved reviewing toolkits; interviews with seven participants, from Designers to Professors; and a design case study by the Author.

Thematic analysis was used to quantify key themes of the interviews to enable synthesis with secondary research and the case study. This analysis led to the inclusive design principles: empathy, community, and diversity.

This poster presents The Inclusive Approach. A methodology that accommodates any project, from the design of a utensil, to avoiding artificial intelligence bias. This research demonstrates using The Inclusive Approach, it is possible to build on the roots of inclusive design to support diversities that better reflect today's society.

Keywords: *design methodology; diversity; inclusive design; empathy*

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