A Monthly Publication of Design for All Institute of India January 2024 Vol-19 No-1 ISSN 2582-8304

Design for All

Critical Inclusive Design

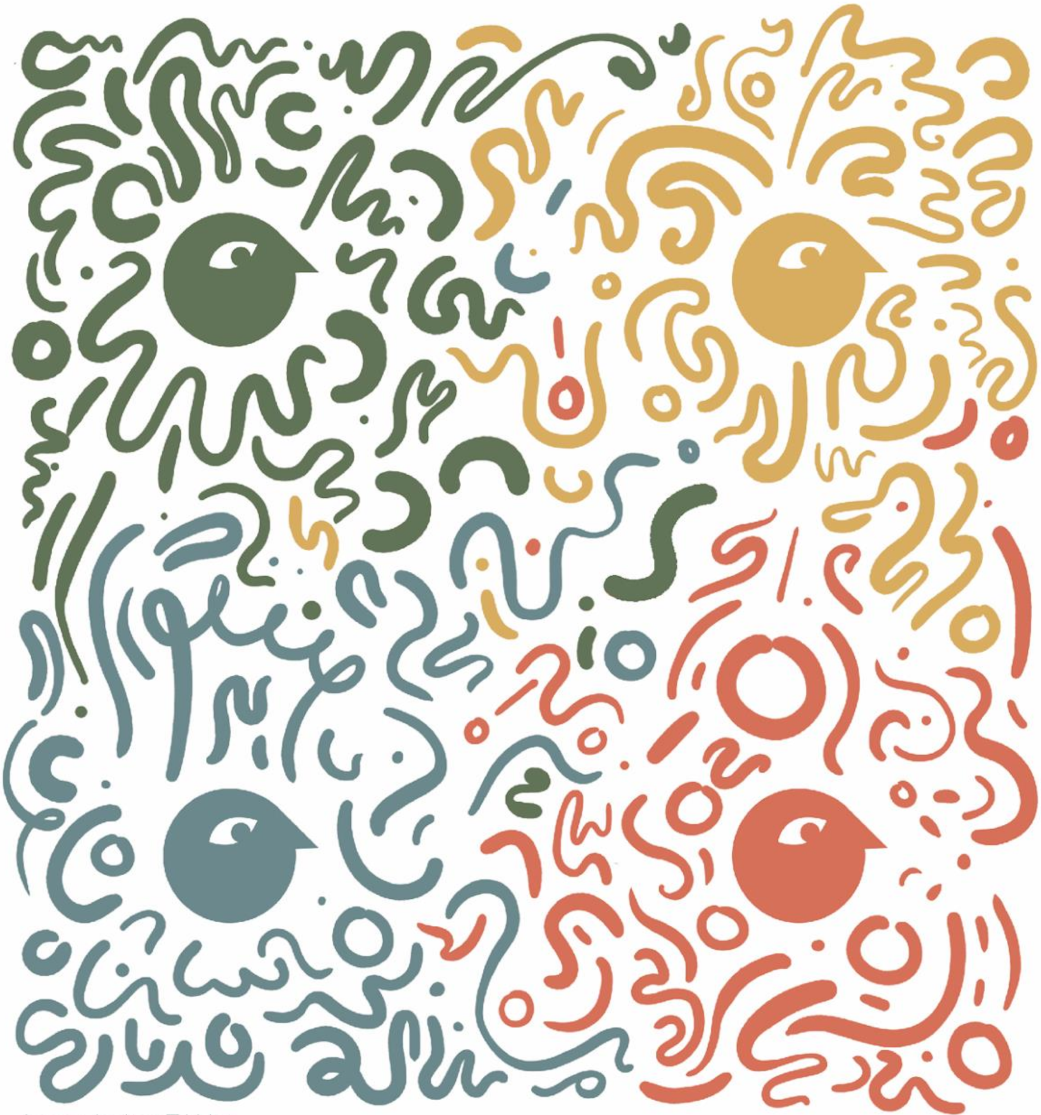


Image: Andrew Tibbles

Special Issue by:

the INCLUSIONARIES
lab for inclusive & human-centred design research

Guest Editor: Dr Farnaz Nickpour
School of Engineering I The University of Liverpool I UK

ISSN: 2582-8304

January 2024 Vol-19 No-1

Guest Editor:

Dr. Farnaz Nickpour is an inclusive and human-centred design scholar, researcher and educator with more than 15 years of experience in leading inclusive design research across healthcare and mobility sectors in the UK, and Director of The Inclusionaries Lab for advanced design research at The University of Liverpool, UK.

Farnaz's research focuses on critical and contemporary dimensions of design for inclusion, aimed at advancing four strategic research themes i.e., Inclusive mobility; Psychosocial inclusion; Inclusive health innovation; and Design for palliative and end-of-life care. Farnaz has an established track record of award-winning design research, education and knowledge transfer, with 50+ peer-reviewed design publications, External Examiner appointments at the Royal College of Art and University of Brighton UK, and various advisory, review and scientific committee positions in international design journals, conferences and organisations.

As the Guest Editor of the inaugural edition of Design for All India, Farnaz will be introducing and outlining the theme of 'Critical Inclusive Design', building the case for critically

engaging with inclusion. With diverse contributions from The Inclusionaries Lab researchers, this edition will provide multiple perspectives, contexts and examples of dilemmas and existential crises inclusive design is facing and sets the scene for a new theoretically and empirically informed field of 'Critical Inclusive Design' - which Farnaz argues is urgently needed.

Editorial:

The Case for 'Critical Inclusive Design'

Inclusive design status quo needs to be challenged and inclusive design state-of-the-art needs to be reimagined and redefined. There is urgency and significance to this statement.

Inclusive design is both a philosophy and a practice. We need to progress both fronts, if we are to remain relevant and impactful as a field. Critical reflections and progressive perspectives on philosophy and positionality of inclusive design are much needed, as well as granular know-how and nuanced guidance on advanced application of inclusive design.

What are the existential crises of inclusive design today? This question, and perhaps more importantly, this critical approach, has significance to our field. As a community of research and practice, we are well aware of many of our dilemmas, while for some others, we need to adopt a transdisciplinary lens - to excavate and define them together with other fields. Going forward, what do we do about these dilemmas and crises, and how do we best capture and communicate them to inform and advance the field? Does this require a more critical, reflexive and collective approach? And as a progressive field, how do we define our position in relation to the more contemporary and critical issues of our time? A quick review might help illustrate an overall picture:

- **On a societal level - Equality, Diversity and Inclusion (EDI) is already at the top of the societal, organisational and educational agenda. This is a major step forward, and prone to tick-boxing and tokenism. This is also a timely opportunity for inclusive design to step in and offer valuable** conceptual/methodological/empirical expertise. How should inclusive design dialogue with and inform EDI and are opportunities for such conversations and contributions being realised? Moreover, what is the juxtaposition of inclusive design and equity? Does inclusive design strive for tackling inequality, or do we strive for designing with equity at the outset? And are we equipped with the principles, methodologies and tools for this?

- On an inter-disciplinary level - is inclusive design actively engaged with important voices and relevant disciplinary epistemologies outside the design field - such as critical disability studies, philosophy of technology, and medical humanities? And as such, how does inclusive design relate and respond to increasingly relevant perspectives such as ethics, rights and narratives of inclusion, exclusion and oppression, intersectionality, and techno-ableism?

- On an intra-disciplinary level - how do we position ourselves in relation to relevant emerging approaches within the design field, such as pluriversal design, system-shifting design, and design justice? How could inclusive design be applied on a transformative system-shifting level, acknowledging relationality and multiple centres, and actively contribute to design justice - moving beyond the equality and equity mandate?

Do we think our inclusive design research and practice agenda and priorities are in keeping with key challenges and priorities of our times, or are we possibly falling behind? Where do we stand now and what is the next stage? What is our long-term vision and what are our key strategy and priorities? What are we doing well,

and what capabilities, connections and commitments do we need to establish? There seems to be a critical, strategic, and progressive void and a state of stagnancy in the inclusive design field - leaving many such questions unaddressed. A more reflexive, positional and transformative approach is needed.

This special edition by the Inclusionaries Lab is a first step towards conceptualising and contextualising 'Critical Inclusive Design', laying the foundations for it as a new field of enquiry, research and practice, addressing some of the above questions and beyond.

The edition presents a selection of articles by The Inclusionaries members Cara Shaw, Luka Kille-Speckter, Andrew Tibbles and Isobel Leason, as well as a joint piece introducing The Inclusionaries as a design research collective. Together, the four articles by each lab member offer a quadruple critical review of the current state of inclusive design as a field through four distinct concept-specific, context-specific, method-specific and tool-specific critical lenses and help outline first insights and initial constructs for a 'Critical Inclusive Design' approach.

A concept-specific critical lens

In "*Identifying 'Extremes' in Complex Systems; Critical and Systemic Perspectives on the Concept of Extreme Users from a Study in Oral Health*", Isobel Leason offers concept-specific critical perspectives on inclusive design by interrogating the concept of 'extreme user' through the lenses of systems, complexity and intersectionality, bias, and categorical and normative thinking. Leason argues, while extreme users notion is foundational to inclusive design, its conventional conceptualisation and application, particularly within the fourth order design domain, fails to acknowledge complexities,

intersecting dimensions, and dynamic boundaries between extremes and mainstreams within a system. Leason suggests advanced perspectives to account for the above and contextualises them within the field of inclusive oral health systems, drawing on her findings from a research study in this area. The article concludes by proposing System's Context; Individual-System Navigation; and Individual's Context as three levels to consider when gauging extremes on a systemic level.

A context-specific critical lens

In "*Advancing Inclusive Design in the Context of Paediatric Mobility; Six Key Research Studies and a Critical Implementation Strategy*", Cara Shaw offers context-specific critical lenses on inclusive design by focusing on the field of inclusive paediatric mobility design. Shaw revisits her six comprehensive research studies in this area and offers distinctive dimensions and perspectives through which to advance inclusive paediatric mobility design. These include Narratives, Children's rights, and Child-centred framing. Shaw starts with a reflexive approach interrogating 50 years of inclusive paediatric mobility design through a mapping review. She then develops theoretical frameworks and models to transition designerly ways, elevate children's voice through analysing their designs, and build theories around design as an agent of narratives to advance the field. Shaw finally proposes a critical implementation strategy offering five practical considerations which shift the focus from knowledge building and design research to knowledge implementation and design practice to ultimately deliver tangible impact in the field of inclusive paediatric mobility design.

A Method-specific critical lens

In "*Influences in Eliciting Authentic Answers in Design Inquiry and Imagination: through the lens of participatory design workshops*", Andrew Tibbles offers a method-specific critical lens, reflecting on the methods of participatory design, particularly participatory design workshops. Tibbles shares scepticisms around authenticity of outcomes of design inquiry and imagination through this method, recounting his multiple experiences over the years as a designer, researcher, facilitator, and participant experimenting with diverse settings and scenarios in participatory design workshops. Tibbles discusses social desirability bias, group and individual dynamics and settings, participant hierarchies, and temporal aspects and how they impact and shape reflective practice. The article poses questions around the rigour of design knowledge building in participatory design, and the role of such methods in relation to supporting versus challenging dominant narratives.

A Tool-specific critical lens

In "*The Illusion of Inclusion: Exploring the Paradox of Simulations and Simulation Toolkits in [Inclusive] Design",* Luka Kille-Speckter adopts a tool-specific critical lens, interrogating use of the widely recognised simulation toolkits in inclusive design. Kille-Speckter examines the potential pitfalls and paradoxes in relying on such simulations to offer insight into and empathy for diverse lived experiences, and questions whether they inadvertently perpetuate the 'illusion of inclusion', ableist and deficit-based views, and unintended exclusion. Kille-Speckter explores simulation versus immersion, focuses on the interrelation of narratives and psychosocial, and offers valuable lessons from three non-design disciplines. The author adds an extra valuable dimension to the investigation by sharing first-hand personal

accounts of her experiences with simulation toolkits as an individual with a visual impairment, through an auto-ethnographic lived experience expertise lens, alongside her disciplinary expertise lens. Kille-Speckter concludes with a set of suggestions to guide designers in adopting a critical and nuanced approach to simulation tools, or as she notes: 'A Call to Do Better'.

Beyond their critical and reflexive content, these four articles exhibit diverse and distinctive approaches to writing, and authorship styles - reflecting the individuality and positionality of their authors in both the choice of topics and the formats of narration. As The Inclusionaries, we believe this is important and something we should strive for.

Collectively, the articles in this edition exemplify a critical and reflexive approach to inclusive design, through interrogating specific and key inclusive design concepts, contexts, methods and tools. Our goal is to build on this first attempt, towards conceptualising and contextualising critical inclusive design as a field.

We hope there is value to the reader and that this edition of Design for All India would stimulate further thinking and conversation within the wider inclusive design community. You can find us at: www.inclusionaries.com - we hope to hear from you to collectively build on critical inclusive design.

Acknowledgement

This edition has been a major team effort and I would like to thank all The Inclusionaries Lab members; Cara Shaw, Luka Kille-Speckter, Andrew Tibbles and Isobel Leason for their enthusiasm, commitment, and excellence as always, also thanks to Andrew Tibbles for leading graphic design work for this special edition.

This has also been a precious opportunity and exercise for us as a team, to reflect, critique and create together as a collective and I would like to thank Dr Sunil Bhatia for this invitation to contribute as a Guest Editor for this Design for All edition.

Dr. Farnaz Nickpour

Director of The Inclusionaries Lab for Design Research.
Design Lead at Department of Materials, Design and Manufacturing Engineering.
Designer-in-Residence at Marie Curie Hospice.
Reader in Inclusive Design and Human-centred Innovation at the University of Liverpool.

Dr. Farnaz Nickpour is an inclusive and human-centred design scholar, researcher and educator with more than 15 years of experience in leading inclusive design research across healthcare and mobility sectors in the UK, and Director of The Inclusionaries Lab for advanced design research at The University of Liverpool, UK. Farnaz's research focuses on critical and contemporary dimensions of design for inclusion and human-centred innovation, aimed at advancing four strategic research themes i.e., Inclusive mobility; Psychosocial inclusion; Inclusive health innovation; and Design for palliative and end-of-life care. Farnaz has an established track record of award-winning design research, education, and knowledge transfer, with 50+ peer-reviewed design publications, External Examiner appointments at the Royal College of Art and University of Brighton UK, and various advisory, review and scientific committee positions.

Cara Shaw

Design Researcher on 'SMART Suit' project.
CTO at The Accessibility Institute.
PhD Researcher at the University of Liverpool.

Cara Shaw is an Inclusive Designer and PhD Researcher who has designed and developed a variety of healthcare and mobility products, from all-terrain wheelchairs and evolvable walking aids to smart exoskeletons and rehabilitation devices. Her work has been recognised by over 15 design awards and her research has been As well as hands-on design and engineering work, Cara has led design research, ethnographic studies and usability trials for a range of companies, start-ups and charity sector organisations internationally.

Cara currently works as a design researcher on the development of an upper-body exosuit for children and young people with progressive neuromuscular diseases. She is also Chief Technology Officer at The Accessibility Institute in Kenya, where she directs and manages the design and development of user-centred assistive technology and mobility products, primarily to support people living in poverty in low-resource settings.

Luka Kille-Speckter

Installation design & third sector consultant.
Design Researcher at MerseyCare LifeRooms.
Visiting Lecturer at HDM, Stuttgart, Germany.
PhD Researcher at the University of Liverpool.

Luka Kille -Speckter is a lived-experience designer, consultant, PhD researcher and educator. Her mixed background of social science, experience design and inclusive design, Luka combines her expertise with her lived experience of visual impairment to outline design opportunities and impact.

Andrew Tibbles

**Designer-in-Residence, Marie Curie Liverpool.
PhD Researcher, the University of Liverpool.**

Andrew Tibbles is a speculative designer and a PhD researcher with a fascination for the consequences of new and emerging technologies on individuals, collectives and societies. His background is in product design and he made a career in makerspaces, creating, experimenting and teaching emerging modern manufacturing techniques and machines across the UK.

What began as a pragmatic honour's year project towards death, dying and beyond, became a source of constant curiosity and is now part of his PhD research in collaboration with Marie Curie Hospice Liverpool; exploring how, why and should technology and artificial Intelligence play a role in the future of hospice care. And what many forms those technologies could take to strive towards a 'good death' in the modern age. Andrew's PhD is funded by Doctoral Network in AI for Future Digital Health.

Isobel Leason

Design Researcher on 'SysteMatic' Project.
PhD Researcher at the University of Liverpool.

Isobel Leason is a design researcher in inclusive healthcare innovation. She was trained in Product Design Engineering and spent time working in the orthodontic technology sector. Her current PhD research, funded by the Doctoral Training Network in Technologies for Healthy Ageing, conceptualises and adopts a Critical Inclusive Design approach in oral health systems to co-define an agenda towards "Oral Health for All". She also works on the SysteMatic project; developing a Systems Engineering Innovation Hub for prevention, precision and equity by design for people living with Multiple Long-Term Conditions (MLTC).

The Inclusionaries Lab; Evolving Perspectives, Practices and Priorities for Advancing Design Research

Farnaz Nickpour, Cara Shaw, Luka Kille Speckter, Andrew Tibbles, Isobel Leason.

Abstract

The Inclusionaries is an award-winning UK-based design research lab focused on advancing the agenda, knowledge and know-how for Inclusive and Human-centred Design across health and mobility sectors and paediatric and adult populations. The collective consists of five core researchers including experienced designers, makers and lived experience experts and the work focuses on four strategic research themes i.e. Inclusive Mobility; Psychosocial Inclusion; Design for End of life; and Inclusive Health Innovation. The Inclusionaries Lab mission is to support organisations, practitioners and researchers in integrating advanced inclusive and human-centred design into their processes and practices. This article outlines the evolving principles, positionality, practices and priorities of the lab as a design research collective.

Keywords

Design research; Research lab, Design collective, Inclusive design, Human-centred design, Inclusive Health, Inclusive Mobility, Positionality, End of life, Psychosocial inclusion, Healthcare innovation.

1. Aim, Philosophy and Impact at The Inclusionaries Lab

The Inclusionaries is a design research lab specialising in inclusive and human-centred research, design, engagement and innovation. The lab investigates critical and contemporary dimensions of inclusive design and human-centred innovation for people, communities, and society. Our work supports organisations, practitioners, and researchers in integrating advanced inclusive and human-centred design into their work.

Figure 1. The Inclusionaries Lab team from left to right; Andrew Tibbles, Isobel Leason, Farnaz Nickpour, Luka Kille-Speckter, Cara Shaw.

1.1 Aim & Scope

The Inclusionaries work actively centres sensitive healthcare and low-resource settings, areas of unmet need, and populations particularly disserved by innovation.

As a design research lab directly informed by and involved in real-world practice, The Inclusionaries has two intertwined goals:

1. **Advancing the agenda, knowledge and know-how for inclusive & human-centred design across healthcare and mobility sectors.**
2. **Advancing health, mobility and equity in disadvantaged groups and marginalised contexts across paediatric and adult populations.**

Importantly, in design research and practice terms, the disadvantaged and marginalised groups, seldom heard voices and underrepresented contexts translate into 'extreme user groups', 'extreme scenarios of use' and 'extreme contexts of use'. Unlike the above though, these design terms and concepts span both ends of the spectrum including 'power users' as well as 'rejectors' which, due to a multitude of complex, contextual and intersectional factors, are not typically included and designed for within mainstream design processes and not catered for within the mainstream provision.

Hence, The Inclusionaries aims to actively:

1. **Acknowledge, identify and engage extreme user groups;**
2. **Speculate, design, develop for extreme use scenarios and contexts to bring them back to centre - in its pluriversal sense.**

1.2 Inclusion; Our philosophy

The Inclusionaries applies inclusive and human-centred design principles to bring seldom heard voices, disparities and experiences from the margins - in design terms, extreme user groups, scenarios and contexts of use - to the centre of design processes, practices and outcomes, and to advance those scenarios and contexts for both extremes and mainstreams.

The distinction, as well as the dynamics between 'mainstream' and 'extremes' - as in the distinction and dynamics between 'centre' and 'margins' - is the underpinning philosophy that shapes and informs our thinking and practice. We believe capturing distinctions and dynamics between the extreme and the mainstream impacts three distinct orders:

1. **Benefiting the WHOLE - acknowledgement of and engagement with margins and peripheries within any system, such as its extreme user groups, scenarios and contexts of use, grants a more critical, reflexive and holistic understanding of the 'nature' of that system, and enables diverse and de-centralised interrogation, improvement, speculation and transition of the system as a whole.**

2. **Benefiting the EXTREME - acknowledgement of and engagement with extreme user groups, scenarios and contexts of use, brings them back to the centre of design processes, practices and outcomes, prevents exclusion by design, and enables inclusive, just and equitable provision.**

3. **Benefiting the MAINSTREAM - acknowledgement of and engagement with a diverse range of design constraints and challenges introduced by extreme user groups, scenarios and contexts of use, enables and affords more innovative,**

nuanced and encompassing design solutions benefiting the mainstream.

We acknowledge the design semantics of ‘extreme’ user/scenario/context might not be conducive across disciplinary or lived experience semantics and may create healthy tensions. We acknowledge the same for the term ‘user’ - albeit it is becoming increasingly nuanced within the design discipline.

1.3 Impact

We define and measure our success through a triple impact agenda focused on knowledge development, exchange and dissemination.

A. Knowledge and Know-how Development & Agenda Setting
Establishing new areas of design research including ‘Psychosocial inclusion’; ‘Design Meets Death’; and ‘Inclusive Paediatric Mobility (IPM) Design’. Advancing design knowledge through design frameworks, guidelines and evidence maps across inclusive mobility, oral health, end of life, and design-led participation.

B. Knowledge Exchange & Advancing Real-World Practice
Leading advanced inclusive and human-centred user research partnerships, product/service/system design research with end-users and stakeholders including co-creation and design discovery processes. Developing innovative inclusive health and mobility solutions including SMART SUIT upper body exoskeleton; SafariShop mobile shop for inclusive livelihood; DBO commode for hospital wards. Initiating award-winning design innovation in health and mobility settings including Designer-in-Residence model for design research in palliative and end of life care.

C. Knowledge Dissemination & Engagement

Disseminating design research through more than 50 peer-reviewed academic publications and invited/organised research engagements across multiple design/non-design platforms. Academic and industry training and end-user and public engagement services in curated workshop/short course/track/seminar formats. Pioneering interdisciplinary design education through teaching design to the medical workforce of the future - establishing a 'Design in Healthcare' course in University of Liverpool School of Medicine MBChB program.

2. Position and Positionality at The Inclusionaries Lab

The Inclusionaries team consists of five core design researchers, including experienced design academics, assistive technology designers, speculative designers and makers and lived experience experts. In introducing the collective, we believe it is important to capture the evolving positions as well as positionalities of each individual design researcher, e.g. the team's backgrounds, expertise & experiences, contexts and perspectives that might inform our work.

Dr. Farnaz Nickpour

**Director of The Inclusionaries Lab for Design Research.
Design Lead at Department of Materials, Design and Manufacturing Engineering.
Designer-in-Residence at Marie Curie Hospice.
Reader in Inclusive Design and Human-centred Innovation at the University of Liverpool.**

Dr Farnaz Nickpour is an Iranian-British design academic, researcher and educator with more than 15 years of experience in UK higher education institutions. Farnaz's design expertise and approach to inclusive and human-centred design is informed by her eurocentric education in Industrial Design and Design Strategy and Innovation in Tehran and London, and shaped through her equity-innovation, user-centric product & service, and critical and contemporary design lenses. As an emigrant, immigrant woman of colour, dual national with duality in culture and value system, and researcher with a criticality-strategy-diversity-innovation value set, Farnaz's work inherently gravitates towards the edges and extremes within a system - to acknowledge, engage and centre them through design. This is evidenced in Farnaz's design research leadership spanning healthcare-mobility sectors and adult-paediatric populations; from design for end-of-life and psychosocial inclusion agenda setting, to establishing award-winning design research/education frameworks for clinical workforce, sensitive health and inclusive

mobility settings; to leading inclusive Med-Tech design for childhood disability and blueprinting systems innovation hubs for people living with multiple long-term conditions.

Cara Shaw

**Design Researcher on 'SMART Suit' project.
CTO at The Accessibility Institute.
PhD Researcher at the University of Liverpool.**

Cara is a British design researcher who has accumulated a breadth of experience in industrial design, human factors engineering and ethnography since her first design engineering job in 2012. She was a first-gen university student in London, studying Industrial design and technology, which shaped her user-centred, interdisciplinary and eurocentric understanding of design. Upon graduating, Cara founded a company to develop assistive mobility devices, motivated by her grandfather's sudden decline in mobility. She went on to co-found a social enterprise 'The Accessibility Institute' (TAI) developing assistive mobility solutions for people living in poverty; her understanding of design for low-resource settings is strongly informed by the time she has spent working in rural Kenya. Cara has since designed, developed and implemented mobility and disability products internationally (Europe, South America, Africa). After several years working on inclusive mobility projects for a range of R&D startups, companies and charity sector organisations, Cara began a PhD at the University of Liverpool, focused on inclusive paediatric mobility design. Cara's design approach tends to focus on design justice, equitable participation and access for all.

Luka Kille-Speckter

Installation design & third sector consultant.
Design Researcher at MerseyCare LifeRooms.
Visiting Lecturer at HDM, Stuttgart, Germany.
PhD Researcher at the University of Liverpool.

Luka is a lived-experience designer, consultant, and PhD researcher with a multidisciplinary background in Social Science and Experience Design. This multidisciplinary foundation shapes her positionality, allowing her to view issues through a lens that often incorporates methods and approaches from social science into her design work. Her lived-experience of visual impairment, coupled with a significant dedication to raising awareness about visual impairment and sensory diversity, is evident throughout her work, reflecting both personal and professional perspectives. This commitment is also reflected in her PhD topic, Psychosocial Inclusion, which delves into the different dimensions inclusion/exclusion can inhabit, including the physical, emotional, psychological, social, and cultural aspects. Luka's introduction to Inclusive Design occurred at its origin, the Helen Hamlyn Center for Design at the Royal College of Art. This early exposure profoundly influences her understanding and approach to inclusive design, adding a rich layer to her expertise and contributing to the nuanced perspective she brings to her work. Luka is deeply committed to fostering a shift from deficit-based, ableist approaches to an understanding of holistic experiences for individuals.

Andrew Tibbles

Designer-in-Residence, Marie Curie Liverpool.
PhD Researcher, the University of Liverpool.

Andrew is a British-born male with his formative years in rural England and his adolescent years in urban Scotland. Studying Product Design (BSc Hons) at the University of Dundee he developed interests in design ethnography, participatory design, speculative design and advanced manufacturing. The teaching also influenced much of his thinking in terms of the responsibility of design and the role play can have on knowledge-making. His career has developed through Makerspaces, first in London, then in Glasgow building his teaching and craft skills. Andrew has experience with design exhibitions as both a developer and exhibitor, his own exhibitions have centred around the topics of Death and AI and Democracy. This has all led to his current PhD topic focused on desirable futures of hospice care, undertaken through an innovative Designer-in-Residence model, situating a designer in the heart of a working hospice, which has won a Culture of Innovation award at the North West Coast Research and Innovation Awards 2023. Andrew's design lens can be summarised as critical democratic societal imagination and change.

Isobel Leason

Design Researcher on ‘SysteMatic’ Project.
PhD Researcher at the University of Liverpool.

Isobel was born and educated in the UK. She has an MEng in product design engineering, which she gained in Glasgow studying across two institutions with distinctive cultures - the School of Design at Glasgow School of Art and the School of Engineering at the University of Glasgow. Her understanding of design is influenced by this education, which was: human-centred, interdisciplinary, euro-centric. Her interest in health innovation developed in university, and since then she spent time working in the orthodontic technology sector in the UK and Turkey. Her interest in oral health in particular, stems from personal experience of significant orthodontic treatment and dental surgery with a difficult recovery period. In recent years, her interest has shifted from healthcare products and technology to health systems and policy. This led to her current PhD research which explores ‘extremes and mainstreams’ in oral health systems, and develops an agenda for transitioning towards inclusive oral health systems. She adopts critical and systemic design approaches, focusing on equity, social justice, and the experiences of people who are often excluded from research.

3. Strategic Research Themes at The Inclusionaries Lab

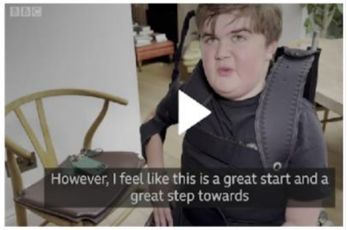
The Inclusionaries Lab's work spans inclusive and human-centred design research across mobility-health sectors and paediatric-adult populations and is focused on advancing knowledge and know-how within four strategic themes: Inclusive Mobility; Psychosocial Inclusion; Design for End of life; and Healthcare Innovation.

Figure 2 provides an overview of the Inclusionaries Lab design research, outlining the lab's Expertise, Themes, Sectors and Impact. It also represents one current design research project from each of the four design research themes at The Inclusionaries Lab;

1. **Inclusive Mobility - Inclusive MedTech Design; designing the 'SMART Suit' exoskeleton for children and young people living with progressive neuromuscular conditions and developing the ICER Framework of design-led participation (PPL Dream Fund).**
2. **Psychosocial Inclusion - Design Exclusion Library; co-creating a library of psychosocial and physical design exclusion scenarios across connected physical and mental health for social prescribing service users (Mersey Care NHS Foundation Trust).**
3. **Design for End of life; Designer-in-Residence; a new model for design-driven research and innovation in future hospice care systems (Marie Curie UK).**
4. **Inclusive Health Innovation; 'SysteMatic' Systems Engineering Innovation Hub; prevention, precision and equity by design for people living with Multiple Long-Term Conditions (NIHR and EPSRC).**

Figure 2. Current landscape of design research at The Inclusionaries Lab in 2023

the
INCLUSIONARIES
lab for inclusive & human-centred design research



A Library of Design Exclusion Scenarios; physical and mental health (**Mersey Care**)

Design-in-Residence; a new model for design-driven innovation in future hospice care **(Marie Curie UK)**

Inclusive MedTech Design; ‘Smart Suit’ Exoskeleton for Children with Progressive Neuromuscular Conditions (**Dream Fund, PPL**)

Systems Engineering Innovation Hub; Multiple Long Term Conditions (**NIHR + EPSRC**)

EXPERTISE

- Inclusive design
- Human-centred design
- Systemic design
- Design Futuring

THEMES

- Inclusive mobility
- Psychosocial inclusion
- Healthcare innovation
- Design for end-of-life

SECTORS

- Healthcare
- Mobility

IMPACT

- knowledge & know-how development
- Knowledge exchange
- Knowledge dissemination & training

3.1 Inclusive Mobility

Inclusive mobility encompasses user-centred design, research and engagement to create products, services and systems which optimise movement and quality of life for mobility-challenged individuals and communities.

Our contributions to inclusive mobility design span adult-paediatric and personal-public dimensions and have been internationally recognised through multiple awards and publications as well as through interventions such as evolvable walking aids, all-terrain wheelchairs and smart exoskeletons - currently in development.

We are currently applying an advanced design research methodology to the 'SMART Suit' project, to develop a first-of-its-kind assistive upper body exoskeleton for children and young people with progressive neuromuscular conditions. We are also working on the development of an all-terrain paediatric wheelchair for low-resource settings through applying child-centred and collaborative methods.

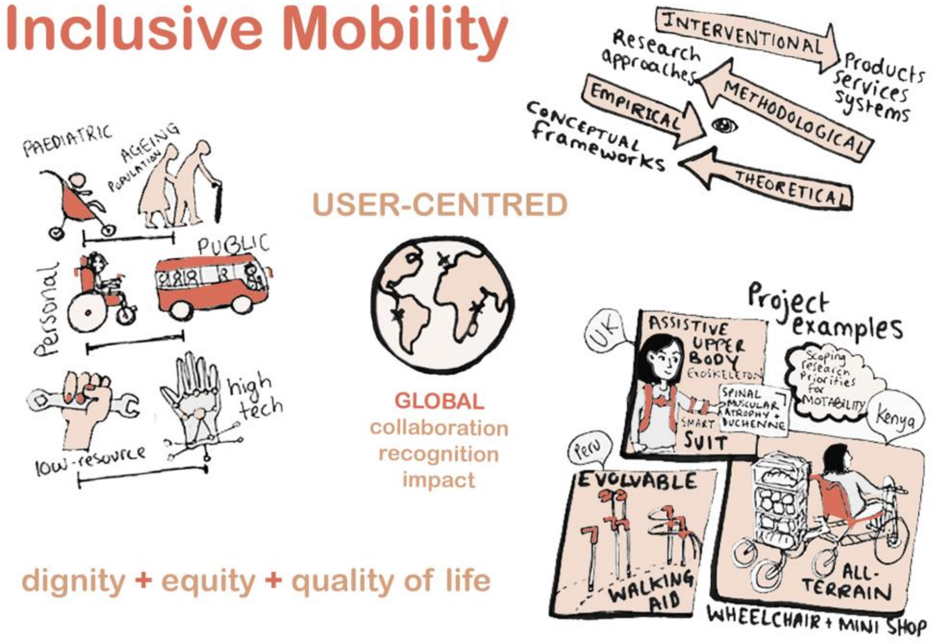


Figure 3. Inclusive Mobility design research at The Inclusionaries Lab

3.2 Psychosocial Inclusion

"Psychosocial Inclusion" coined by the Inclusionaries 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", aims to unpack and shift design inclusion narratives away from physical, ableist & deficit-based, medical models of disability onto experience-led, person-centred & capabilities-based, social & design models of disability.

Our past research has established the formal definition and four constructs of Psychosocial Inclusion in Design (mobility and shopping context) and offered a first timeline review of narratives and milestones of design for disability. Our current research focuses on developing a library of design exclusion/inclusion scenarios in the context of connected physical and mental health.

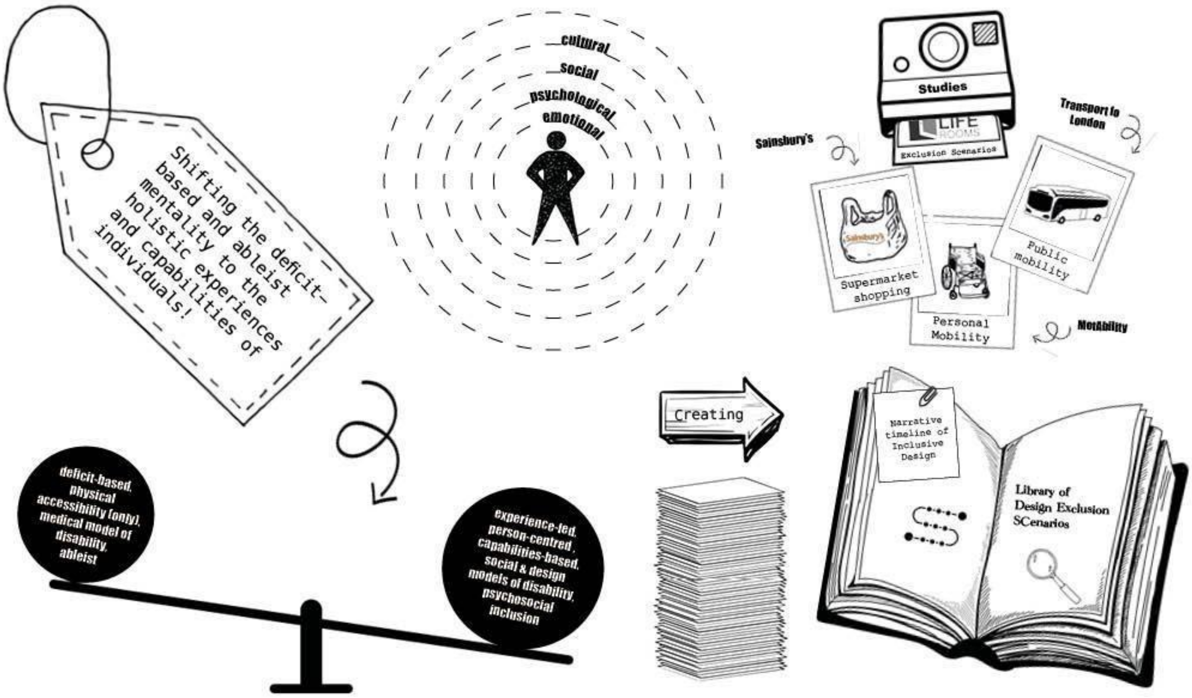


Figure 4. Psychosocial Inclusion design research at The Inclusionaries Lab

3.3 Design for End of life

Coined as '*Design Meets Death*', our work aims to establish a theoretically and empirically informed discourse between the two fields of design and end-of-life to identify critical questions, strategic opportunities, and significant contributions. For this, we adopt design-led framing; system-shifting design; design futuring; inclusive & human-centred design; and transdisciplinarity and place-based lenses & principles.

Our work has resulted in a first systematic mapping review of design contributions to end-of-life field providing granularity on the state of the field, and revisiting 'legacy' in the sensitive context of paediatric palliative care. We are currently pioneering an award-winning Designer-in-Residence programme within hospice care, taking a systems approach to understanding end of life care complexity. This includes mapping the relations within the system grounding us in the reality of today and using participatory asynchronous workshops and speculative design methods to reimagine leverage points that are value-driven and technologically supported.

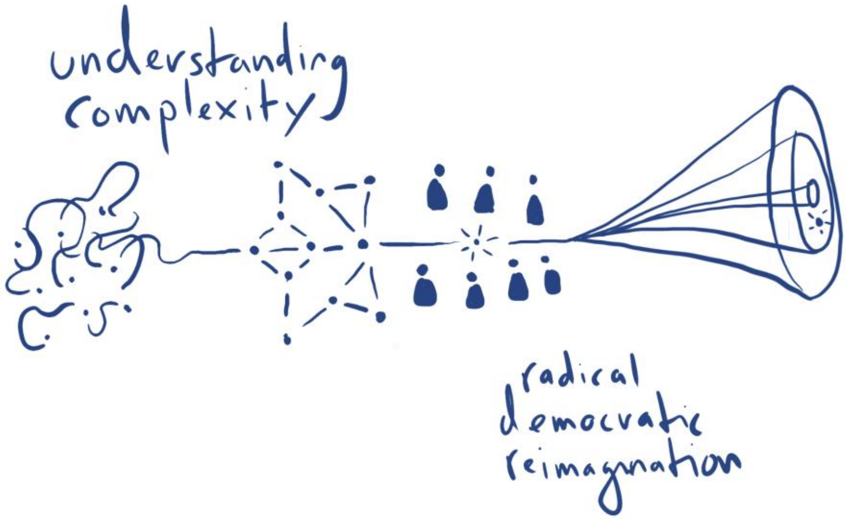


Figure 5. Design Meets Death research at The Inclusionaries Lab

3.4 Inclusive Health Innovation

Health, health and social care equity, and a just society are interconnected. Our Inclusive Health Innovation theme examines health in a wider systemic context to develop effective and equitable healthcare products, services and systems, to improve health outcomes, and to prepare the next generation of healthcare professionals.

We applying advanced inclusive and human-centred design principles, mindsets and processes, with lenses of complexity and intersectionality to focus on health disparities, in particular extreme scenarios in the two contexts of oral health and multiple long-term conditions where extreme users tend to have poor health outcomes.

We are interested in transdisciplinary application of design in healthcare, and lead a first design education initiative at the School of Medicine at The University of Liverpool, aiming to embed design within healthcare education. We are also currently the Design lead in the 'SysteMatic' project, developing a systems engineering innovation hub for people living with multiple long-term conditio

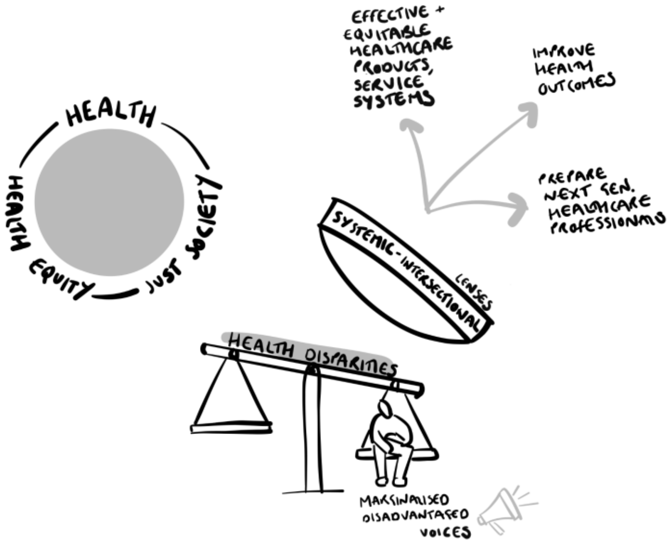


Figure 6. Inclusive Health Innovation research at The Inclusionaries Lab

4. Principles and Priorities at The Inclusionaries Lab

As a collective of design researchers, The Inclusionaries believe it is important to be critical and reflexive about our evolving perspectives, positionalities, practices and priorities. Since establishing in 2019, certain existing and emerging principles, mindsets and practices have become increasingly core to our design research, informing and underpinning our work and shaping and unifying our approach.

The evolving, emergent, critical and uniting nature of these principles and priorities is particularly noteworthy. We aim to capture them as they stand in 2023.

4.1 The Inclusionaries Definition of Design

Our work is increasingly situated within wider systems involving inter-disciplinary partnerships, complex real-world contexts and non-design collaborators and clients, where the term 'design' is ubiquitously used and divergently interpreted. Hence, we have learned to communicate what we define as 'design' with our potential audiences proactively, at the outset, and in a succinct and tangible manner. Figure 7 presents The Inclusionaries definition of 'design'. As a design research lab, we define 'design' through three distinct lenses of design Epistemology, Praxiology and Ontology:

1. Design Epistemology [design knowing]: Design as a discipline that employs a combination of design-led principles, mindsets, knowledge sets, methodology sets, and skill sets.
2. Design Praxiology [design doing]: Design as a process of problem-framing and generating new possibilities that employs a subsequent range of design practices, tools and

methods.

3. **Design Ontology [design output]: Design as a generator of contributions across four types (Theoretical - Methodological - Empirical - Interventional) and outcomes across four orders (Visual - Product - Service - System).**

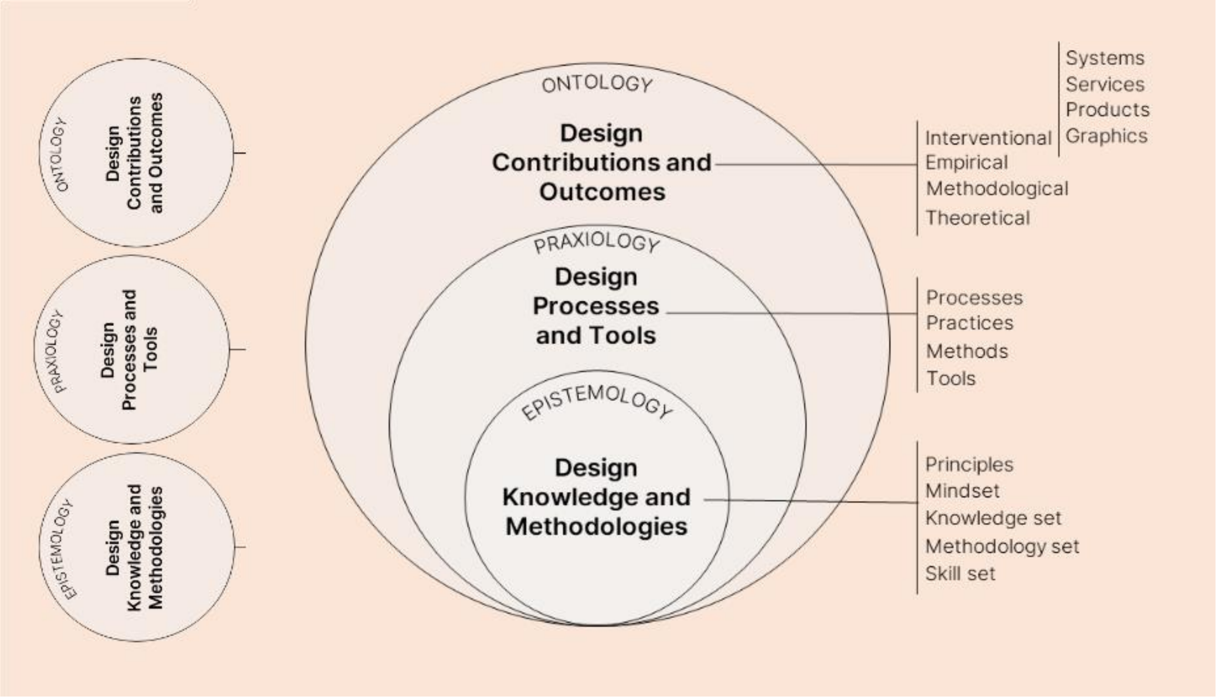


Figure 7. Definition of 'Design' by The Inclusionaries Lab

4.2 The Inclusionaries Positionality

Beyond individual positionality, we believe it is important to acknowledge the multiple contexts and evolving aspects that could inform and influence our collective design research approach as 'The Inclusionaries Positionality'.

- **Identity**
  Predominantly female (4-1) and white European from Scottish, rural English and German ethnicities, including an Iranian. Experiences of dual nationality and duality in culture.

- **Education & Work**
  Eurocentric industrial and product design education

delivered through design & engineering faculties of knowledge, with the exception of one member's social science background. High academic performance and achiever archetype. Work experience in non-corporate, entrepreneurial and freelance design practice and institutional design research.

- Knowledge Expertise
  Inclusive & human-centred design perspectives mainly informed through the lenses of diversity, innovation, good design and user-centred processes, as well as lived experience.

- Research paradigms
  Design research that is reflexive, perspective-building and primarily qualitative, and employs ethnography, phenomenology, and narrative inquiry to explore and interpret subjective meanings. Philosophical stance is primarily constructivist, interpretivist and critical.

4.3 The Inclusionaries Lens

Our work actively incorporates and continually surfaces principles and priorities which characterise our design research approach and are foundational and evolving in nature. We believe it is essential to document and interrogate these as they shape us and we inform them.

Values & Principles

- Social Justice, Equity and Inclusion
- Pluriversality and Relationality
- Criticality and Reflexivity
- Interrogation, Navigation, Speculation and Transition
- Theoretical & Methodological first, Empirical & Interventional second

Mindsets

- **Agenda setting**
- **Knowledge building**
- **Evidence mapping**
- **Sensemaking**
- **Perspective and landscape building**
- **Narrative interrogating**
- **Intersectionality mapping**
- **Transdisciplinarity facing**

Knowledge and Methodology sets

- **Constructivist and Interpretivist**
- **Inductive and Abductive**
- **Exploratory and Descriptive**
- **Qualitative and Empirical**
- **Ethnographic, Phenomenological and Narrative Enquiry based**

5. Going Forward

As an inclusive and human-centred design research collective and a group of individuals, we believe the future will bring inevitable change, shifting our structures, approaches and priorities - whether that change will be transformative is to be seen. Where we stand at this point in our own history and trajectory is unique, meaningful and inspirational to us. We hope and strive for it to be impactful and significant to the multiple worlds in which we exist. As Kurt Vonnegut puts it, *"I want to stand as close to the edge as I can, without going over. Out on the edge you see all kinds of things you can't see from the centre".* And in the words of James Baldwin, *"not everything that is faced can be changed, but nothing can be changed until it is faced".*

Isobel Leason

Design Researcher on 'SysteMatic' Project.
PhD Researcher at the University of Liverpool.

Isobel Leason is a design researcher in inclusive healthcare innovation. She was trained in Product Design Engineering and spent time working in the orthodontic technology sector. Her current PhD research, funded by the Doctoral Training Network in Technologies for Healthy Ageing, conceptualises and adopts a Critical Inclusive Design approach in oral health systems to co-define an agenda towards "Oral Health for All". She also works on the SysteMatic project; developing a Systems Engineering Innovation Hub for prevention, precision and equity by design for people living with Multiple Long-Term Conditions (MLTC).

ISSN: 2582-8304

Identifying 'Extremes' in Complex Systems; Critical and Systemic Perspectives on the Concept of Extreme Users from a Study in Oral Health

Isobel Leason

Abstract

The concept of 'extreme users' in inclusive and user-centred design serves as a valuable starting point for engaging with seldom-heard voices, uncovering latent user needs and fostering innovative design solutions. However, little attention is often paid to the biases and assumptions inherent in the identification and prioritisation of extreme users, and questions could be raised of the concept's value and relevance amidst the dynamic and expanding landscape of contemporary design research and practice. Within the domain of 4th order design (systems and policy), the conventional conceptualisation of extreme users, based on a single axis of product/service use, falls short in acknowledging complexities, intersecting dimensions and dynamic boundaries between extremes and mainstreams in complex systems. This article explores some critical and systemic perspectives on the concept of extreme users, drawing upon examples from research into inclusive oral health systems.

Keywords

Extreme user; Healthcare; Health systems; Oral health; Critical; Systemic; Inclusive design.

1. Context and Motivation

1.1 Reflections and Questions on the Concept of Extreme Users

Inclusive Design (ID) centres on designing with/for often ignored, marginalised or excluded populations. At the heart of ID lies the concept of 'extreme users'; offering designers a systematic means to recognize and engage with individuals and communities central to ID processes. These extreme users occupy the outer edges of the user spectrum; characterized by their unique abilities, specific needs, or unconventional usage patterns. By focusing on extreme users, ID aims to uncover insights that can inform the development of solutions benefiting both the margins and the mainstream.

Engaging with extreme users features in prominent human-centred design kits from IDEO (IDEO, n.d.) and Stanford d.school (Hasso Plattner Institute of Design at Stanford, n.d.), and ID processes often start with identifying an extreme user or scenario. However, often, little reflection is made on how we identify and prioritise these extremes - do our choices, consciously or not, reinforce certain biases and assumptions? Being driven by justice means not just designing inclusion for the underrepresented groups already highlighted or speaking out, but also for others who haven't yet raised their voices or have little or no power to do so.

Additionally, how can we identify and understand extreme users in a complex systems context? The application of ID and the consideration of extreme users in 4th order design (systems and policy) has been limited thus far, however, they are potentially relevant. In serving a complex system in flux, the mainstream inevitably shifts, leaving design solutions based on a previous

mainstream inadequate. Instead, engagement with extremes grants a more critical, reflexive and holistic understanding of the system, enabling robust interventions and long-term system transitions. To identify and understand extreme users in this context, advanced perspectives are required which acknowledge complexities, intersecting dimensions, and dynamic boundaries between extremes and mainstreams.

1.2 Application in Oral Health Systems

This article explores the above questions, drawing from my doctoral research in oral health systems. Interestingly, the language of "extremes" is not unfamiliar in healthcare literature, as evident in discussions on "extreme consumers of healthcare" (Rafiq et al., 2019), and "extreme oral health" (Freeman et al., 2020). Moreover, from a design perspective, parallels could be drawn between the concept of extremes and mainstreams and attitudes towards, oral health and oral healthcare as outside of mainstream health and healthcare provision (Benzian et al., 2011) - despite evidence of the links between oral health and systemic health (Kane, 2017).

I suggest that ID, and the concept of extreme users, is highly relevant and potentially valuable to the pressing issues of oral health inequalities and equity, and current policy-driven transitions towards inclusive oral health systems (Leason et al., 2022). How those at the margins of oral health systems are framed and understood is significant, as it informs approaches to oral health inequalities. Current public health framings have been criticised as reductionist and deterministic (McMahon, 2023). Here, ID offers alternative and complementary approaches for understanding the extremes and mainstreams of the system, and uncovering valuable insights to inform transitions towards inclusive oral health systems. My research in oral health explores these notions of 'extreme users' and 'extreme oral health' through a series of online surveys, interviews, public engagement and stakeholder workshops. The aim is to uncover definitions, dimensions and stories of mainstreams and extremes in oral health systems, and explore how these could be used to co-define an agenda for transitions towards "Oral Health for All" (Glick et al., 2021).

2. Definitions and Representations of Extreme Users

2.1 Terminology

As with much of design terminology, definitions and applications of the concept of extreme users vary. Table 1 presents an overview of terminology used in ID and similar fields relating to the concept of extreme users. Some definitions centre around disability, while others emphasise design interaction. Some simply equate extreme users with exclusion, whereas others distinguish two distinct types of extreme user i.e. power users and non-users/rejectors. The diversity in these definitions is influenced by the author's background and the specific context in which they are developed.

Term	Definition
Extreme user	"Instead of the more typical mainstream design that aims to design for the average user or 80% majority, extreme user design aims to design for the other 20% or the users who are expected to be most affected by the design." (Hahn-Goldberg et al., 2022) "People who do things in ways that average

	consumers tend not to think about." (Donovan, 2020) **"Determining who is an extreme user starts with considering what aspect of your design challenge you want to explore to an extreme. List a number of facets to explore within your design space. Then think of people who may be extreme in those facets." (Hasso Plattner Institute of Design at Stanford, n.d.)**
Edge user	**"Individuals and communities who are either excluded or struggle to access or use a product or service." (Report: Research Reveals Inclusive Design Can Expand Customer Reach Fourfold - Centre for Inclusive Design, n.d.)**
Extra-ordinary user	**"An individual person who happens to have a specific disability, as well as a range of other characteristics which are important for defining them as a person, but may not be related to their disabilities" (Pullin & Newell, 2007)**
Critical user	**"Users with severe disabilities (motion, sensory or cognitive impairments) who can illustrate the extreme end of the usability spectrum and on whom the impact of poor design is greatest in terms of function and stigma" (Dong et al., 2005)**
Lead user	**"People who make greater demands on a product, system, service or environment and therefore challenge it in ways beyond that of the average, mainstream user" (DOGA, n.d.)** **"A lead user is an active and experienced individual**

	engaged in modifying and developing products for personal gain" (Pajo et al., 2015)

Table 1: Definitions relating to extreme users

With terminology associated with similar populations being common both within design and other disciplines such as oral health, it is useful to distinguish the meaning and position of 'extreme users' in relation to these. Table 2 presents a spectrum of neighbouring terminology and definitions from design and health.

Term	Definition
Vulnerable	"In need of special care, support, or protection because of age, disability, risk of abuse or neglect." (Office for Health Improvement & Disparities, 2022b)
Marginalised	"Individuals, groups or populations outside of 'mainstream society'." (Schiffer & Schatz, 2008)
Seldom heard	"Under-represented people who use or might potentially use health or social services and who are less likely to be heard by these service professionals and decision-makers." (Healthwatch, n.d.)
Under-served	"Those experiencing socioeconomic deprivation; those with any of the protected characteristics described in the UK 2010 Equality Act; those not registered with a General Practitioner (GP);

	homeless people; rough sleepers; asylum seekers; gypsy and traveller groups; sex workers; those in prison; those experiencing severe and enduring mental health problems, drug or alcohol harm issues or communication difficulties." (Office for Health Improvement & Disparities, 2022a)
Inclusion health groups	"People who are socially excluded, typically experience multiple overlapping risk factors for poor health (such as poverty, violence and complex trauma), experience stigma and discrimination, and are not consistently accounted for in electronic records (such as healthcare databases)." (Public Health England, 2021)

Table 2: Neighbouring terminology

2.2 Visual Representations

Visualisations are frequently provided alongside definitions of extreme users, commonly using a bell curve, representing the user spectrum, with extreme users at the edges (Figure 1). This visualisation highlights two types of extreme at each end of the spectrum i.e. non-users/rejectors and power users.

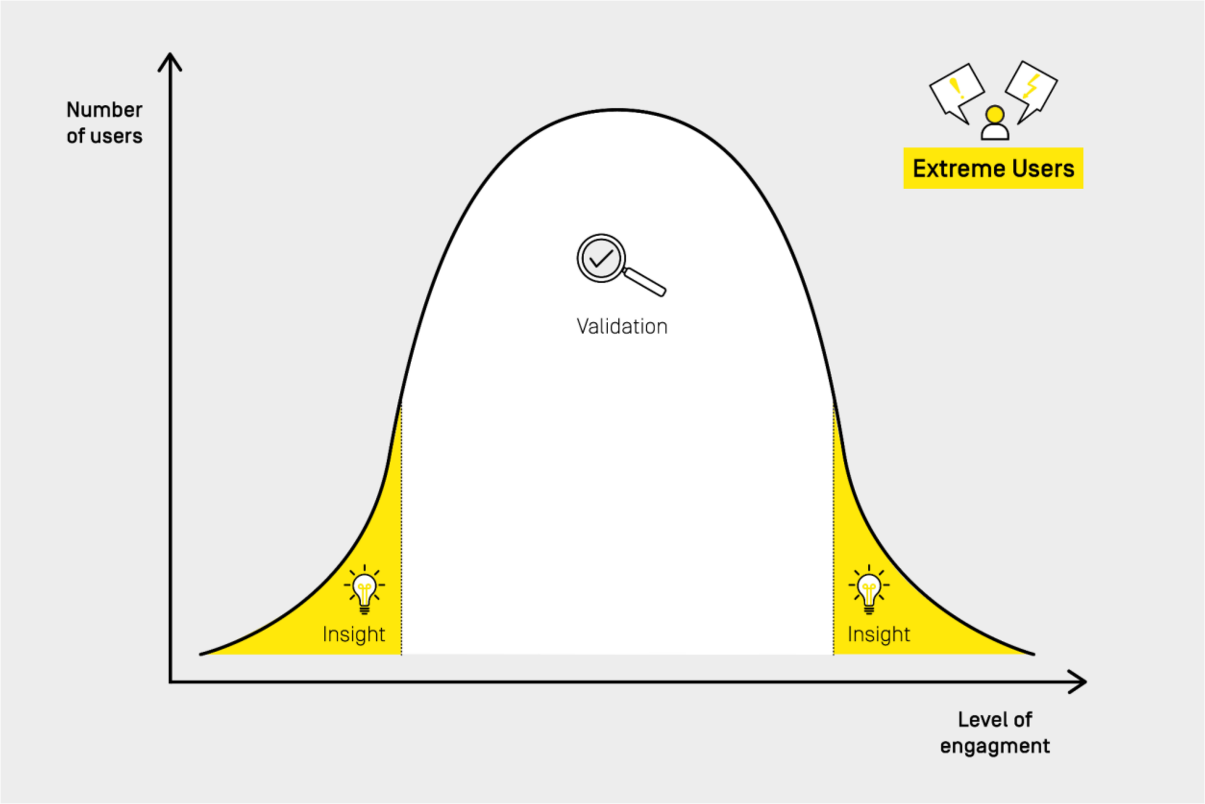


Figure 1: Bell curve representation of extreme users (Meier, 2022)

The bell curve is a familiar visual for designers, however, such visualisations could be criticised as reductionist, simplifying the complex and diverse nature of people and multiple dimensions defining extremes and mainstreams. Moreover, one could question the very concept that there is a single 'normal' user, or a 'normal' distribution of users.

Treviranus (2018) offers an alternative visual of extreme users, using a 3-dimensional representation of a normal distribution - a starburst (Figure 2). This illustrates the complex and interconnected dimensions at play, but it doesn't so clearly visualise both ends of extremes i.e. the idea of power users.

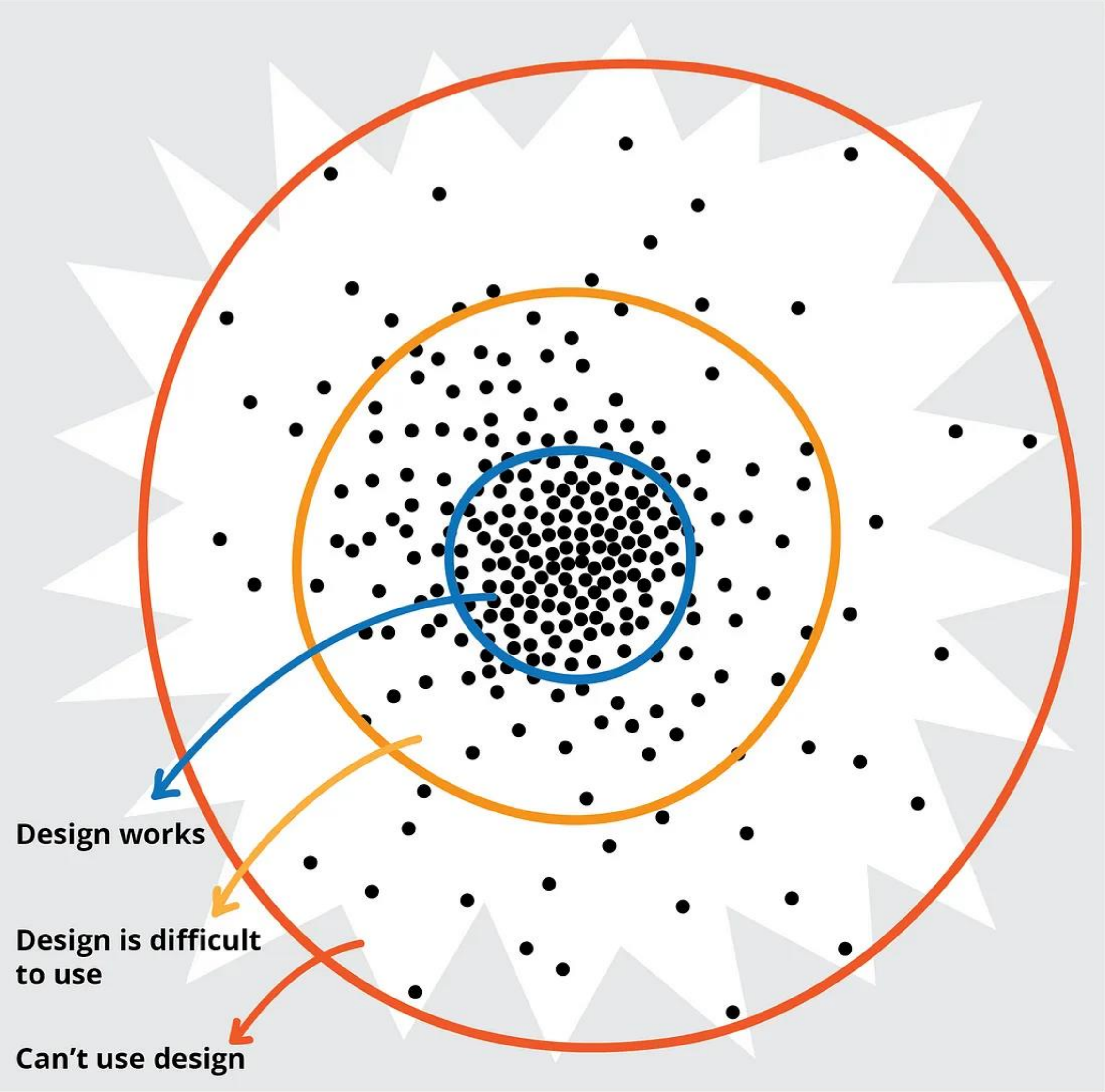


Figure 2: Starburst representation of Extreme users (Treviranus, 2018)

Notably, while there are numerous visualisations and frameworks of determinants of health inequalities, no visualisations are commonly associated with any of the terminology in Table 2. This absence of visual representations may stem from the origin of extreme users within design, where visual communication is a prominent medium. Designers inherently gravitate towards visualising concepts for clarity and comprehension. However, the distinction also lies in the nature of the neighbouring terms, which predominantly describe specific population groups without contextualising them in relation to interaction with a product/

services/system. Unlike extreme users, these terms often lack a comparative dynamic with the mainstream, emphasizing vulnerability, marginalization, or underrepresentation without explicitly addressing their relationship with a normative reference point. This discrepancy highlights the unique positioning of extreme users as a concept.

2.3 Distinctions and Positionality of the Extreme User Concept

Following interrogation of these definitions and representations of extreme users and related concepts, I suggest three important distinctions of the extreme user concept:

1. Extremes are defined in relation to a mainstream. Identification and investigation of extremes requires a reference to something else. While this relational aspect is inherent in much of the neighbouring terminology (e.g. marginalised, socially excluded, seldom heard), none of these provide terminology for, or explicit recognition in definitions/representations of, a 'mainstream'. By explicit recognition of the mainstream, the extreme user concept lends itself to recognising the fuzzy boundaries and dynamics between the extremes and mainstreams.
2. Extremes users lie upon a spectrum(s) including both non users/rejectors and power users - both are useful to learn from. This is a distinction from a focus on excluded or marginalised populations, which recognises a spectrum and highlights power users.
3. Extreme is not an inherent individual trait or demographic group. It is a result of a mismatch with a product/service/system, that anyone could experience at any point (this could be for a short or a long time, and in one specific situation or multiple situations).

3. Critical Perspectives on the Concept of Extreme Users

This section presents some critical perspectives surrounding the concept of extreme users, supported by some examples and considerations from my research in oral health.

3.1 Inherent Bias in Identification and Prioritisation of Extremes

Description:

The process of identifying extreme users and deciding which to prioritise carries inherent biases, subject to observer-dependent contexts and judgments. It is easy to reinforce existing stereotypes or overlook certain groups, leading to skewed representations of extremes.

Example from oral health:

Oral health literature (dental public health, dental epidemiology, special care dentistry, inclusion oral health) and oral health professionals (practitioners, providers and policymakers) included in the research, identify extremes based on a range of factors such as: ability or motivation to access services, frequency of attendance (interaction with system), clinical need, oral health behaviours, oral health status, health status/medical history, lifestyle behaviours and social groups. Some of the different types of extremes identified by participants are shown in Figure 3. Often, the specific populations or individuals identified related to the professional experiences and contexts. It is important to capture all of these perspectives in order to get a more holistic picture of the extremes in oral health systems, as viewed from a diversity of system actors.

Some extremes within oral health may attract heightened attention and acknowledgment within research and policy, while others may inadvertently go unnoticed, slipping into the crevices

between service provisions and thereby perpetuating disparities in care. For instance, individuals with complex clinical needs might be recognised as extreme on one scale, yet find effective accommodation through specialist services. Conversely, those with less acute care needs, despite being less extreme on the clinical scale, might not receive adequate accommodation, illustrating a nuanced disparity in attention and provision.

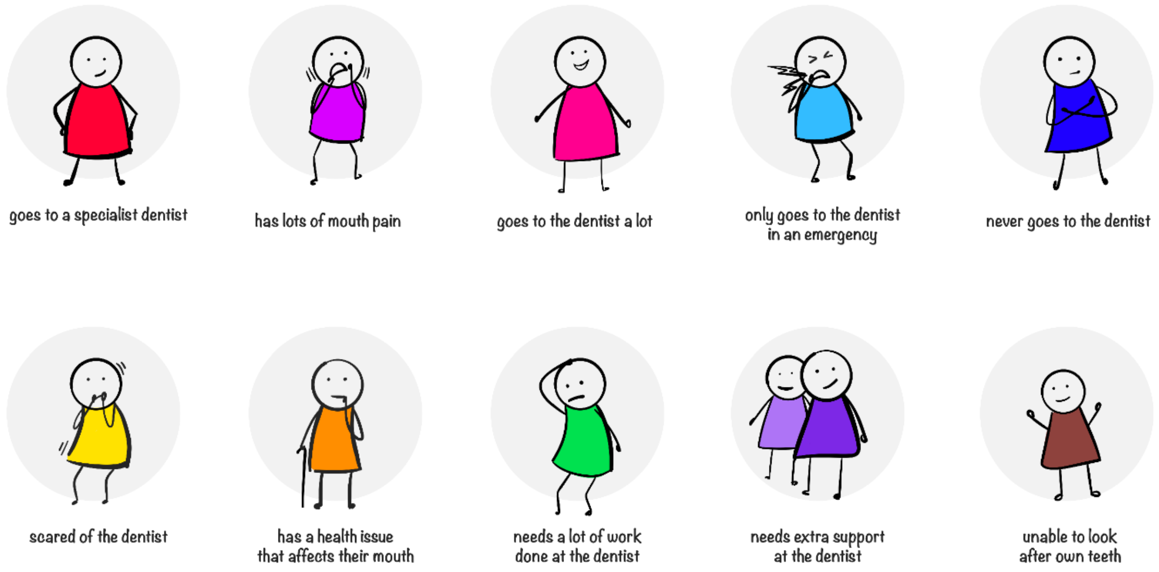


Figure 4: Some of the types of extreme users identified in oral health

3.2 Normative Assumptions

***Description:* The notion of 'extreme' conventionally implies a singular normative baseline, which may not adequately represent the diverse and evolving nature of reality.**

Example from oral health:

In dentistry, the normative assumption may manifest when considering individuals who do not visit the dentist regularly. In certain contexts, these non-users might be categorised as extreme, deviating from the assumed norm of regular dental attendance. However, research participants have astutely pointed

out that non-users are, in fact, a common occurrence within the population. Moreover, the notion of an average utilisation of dental services is challenged, as there exists a broad spectrum of patterns and behaviours in accessing oral health care. This challenges the utility of categorizing extremes in oral health systems along a singular axis of use, recognizing that different norms may prevail in various contexts. The acknowledgement of context-specific normative baselines is crucial for a more nuanced and culturally sensitive understanding of what constitutes extremes and mainstreams in oral health systems.

3.3 Language

Description:

The use of the term 'extreme' in the context of user categorisation can perpetuate othering language, which, consciously or not, may reinforce stereotypes and power dynamics.

Example from oral health:

Several public and professional participants expressed discomfort with the label "extreme," with one participant drawing a parallel to the term "extremist," highlighting the negative connotations associated with such language. This reaction underscores the potential for linguistic choices to carry unintended, stigmatising implications. Oral health professionals also commented on the language, emphasising the importance of adopting language that is widely recognised across the system, promoting inclusivity and avoiding the reinforcement of negative stereotypes. However, the value in diverging from individual trait-based categorisation and instead identifying individuals or groups based on specific situations, patterns of use, or behaviours was recognised as constructive.

3.4 Dangers of Categorisation

Description:

Efforts at categorisation tend to compress the richness of individual experiences.

"When we categorize, we compress category members, treating them as more alike than they are; we amplify differences between members of different categories; we discriminate, favoring certain categories over others; and we fossilise, treating the categorical structure we've imposed as static." **(The Dangers of Categorical Thinking, n.d.)**

Example from oral health:

Conventional dental public health approaches often identify and categorize entire population groups, such as those deemed 'vulnerable,' 'marginalised,' or 'disadvantaged.' This tendency to treat these groups uniformly overlooks the unique and varied needs of individuals within each category. In essence, by adopting a broad categorisation lens, the nuances and complexities of individual experiences and requirements are disregarded. Acknowledging, identifying and engaging with extremes in oral health systems necessitates a departure from such categorical approaches. The focus should shift towards acknowledging the diversity within these groups, ensuring that interventions and strategies are tailored to address the specific needs and circumstances of individuals rather than relying on broad categorisations that risk oversimplification and neglect of individual nuances.

3.5 Complexity & Intersectionality

Description:

Extreme users, if defined based on a single dimension (e.g., disability or usage intensity), may oversimplify the complex

intersectionality of users' identities and experiences. Extreme users identities are interconnected and multifaceted. Overly simplifying these identities risks overlooking the nuanced intersections of characteristics, experiences, and needs.

Example from oral health:

Some oral health professionals involved in the research underscore the complexity and interdependence of the challenges faced by extreme users. Participants said that individuals often navigate *"overlapping and interdependent systems of discrimination or disadvantage".* The acknowledgement of multiple factors at play highlights the intricate web of circumstances that extreme users contend with, making their access to care a compound challenge. *"For extreme users the number of these factors increases and becomes insurmountable circumstances for accessing care".* This example links to the next section on systemic perspectives on the concept of extreme users, and emphasises the importance of embracing a holistic understanding of extreme users that goes beyond isolated dimensions and considers the myriad ways in which their identities intersect, shaping their unique needs and challenges.

4. Systemic Perspectives on The Concept Extreme Users

This section outlines some systemic perspectives, shedding light on the important broader contextual influences that shape the concept of extreme users and need to be considered within oral health systems.

4.1 System as the Cause of Extremes

Description:

System norms, regulations, and practices shape the criteria used to define extremes and mainstreams.

Example from oral health:

One oral health professional said, *"these [extremes] are set against systemic norms that make assumptions about service users"*. The boundaries moderating the extreme and mainstream are determined through policy and commissioning choices (e.g. mainstream and specialist services). Current oral health services and policies incentivise care for some while excluding others. It is also a system driven by the treatment of disease rather than prevention.

4.2 Narratives Around Extremes

Description:

Diverse narratives surrounding extreme users significantly influence how they are both defined and treated within various systems. The perspectives and stories crafted around extreme users shape the discourse, policies, and prioritisation strategies, ultimately impacting the allocation of resources and attention.

Example from oral health:

In the context of oral health, professionals' narratives play a pivotal role in shaping priorities and care strategies. When queried about future priorities, a notable sentiment emerged among some oral health professionals who questioned the need for prioritising extreme users. Some professionals expressed reservations, contending that extreme users are already adequately supported or that focusing on them would potentially delay the care provided to other users. These narratives reflect differing viewpoints on resource allocation and care distribution within the oral health system. While some argue for prioritising extreme users to address their unique needs and reduce significant demand on oral health systems, others caution against such prioritisation, emphasising the perceived availability of

existing support and expressing concerns about potential delays in catering to the broader population. The example highlights how narratives, be they supportive or cautionary, contribute to the shaping of policies and practices, influencing the trajectory of oral healthcare priorities and resource allocation. Understanding and unpacking these narratives is essential for developing a comprehensive and equitable approach to meeting the diverse needs of all users within the oral health system.

4.4 A Plurality of 'Mainstreams'

Description:

Systemic design isn’t bound to singular specific outcomes. It embraces plurality and aims to identify, develop and stimulate interventions to change and adapt the system in some way. In this context, the concept of a singular 'mainstream' is challenged. Embracing pluriversality acknowledges that there are multiple valid centres within a system.

Example from oral health:

Stakeholders emphasise that mainstreams can diverge significantly between and within specific service areas (e.g. specialist services) or contextual settings. This underscores the significance of where we choose to place the frame of reference or central focus. A recurring theme uncovered in our oral health research accentuates that, in the context of oral health services and systems, a non-user should not be perceived as a minority; their experiences and needs hold substantial relevance within the broader framework.

4.5 Language

Description:

The notion of labelling individuals as 'users' of systems prompts critical questions about the appropriateness of such terminology.

This inquiry extends to the definition of extreme users – whether they are accurately characterised by the manner in which individuals use or interact with systems, or if their extremeness is a result of broader systemic determinants. The linguistic choice of terming individuals as 'extreme users' warrants careful consideration to ensure alignment with the nuanced realities of their experiences within complex systems.

Example from oral health:

labelling someone as an 'extreme user' may not fully encapsulate the complexities involved in their experience of oral health. Individuals enduring extreme oral health might be considered ‘extreme’ in an oral health system. This might not be because of their behaviour or experience as a user, but also by systemic barriers, economic disparities, and societal factors. In such cases, the term 'extreme users' may fall short in capturing the comprehensive landscape of influences contributing to their circumstances. This example underscores the need for a careful examination of language choices, advocating for terminologies that aptly reflect the intricate interplay between individuals and systemic determinants within the oral health domain.

5. Identifying Extremes in Complex Systems

The research into definitions and dimensions of extremes in oral health systems, described above, is ongoing. However, in this section I offer some initial sense-making relating to the identification of extremes in complex systems. Table 3 outlines some dimensions relevant to identifying extremes in complex systems; each with a translation in oral health. These should not be considered in isolation, or as single axes on which extremes sit, but as interrelated dimensions than can (in combination) help

to identify extremes. The dimensions are separated into 3 interrelated levels:

(1) System Context:
The system context serves as the foundational layer, representing the external factors that shape the oral health system and establish the mainstream.

(2) Navigating the System:
This represents the pathways and interactions that individuals take within the oral health system. The nature of these interactions and scenarios can determine an extreme.

(3) Individual Perspectives and Experiences:
Individual perspectives and experiences are influenced by both the system context and the navigating layer. They include beliefs, experiences and characteristics that might lead to someone being extreme within a system.

An extreme user is someone whose interactions with the system deviate significantly from the norm or average, influenced by systemic factors, the pathways they navigate, and their individual experiences and perspectives.

Dimension	**Translation in Oral Health**
(1) System Context	
Goal of the system.	**The goal of an oral health system (at various international, national, local levels) might prioritise treatment, prevention, equity, holistic well-being, or patient-centred care - each bring nuanced perspectives on identifying**

	extremes.
System-defined boundaries.	**The way specialist/secondary dental care services are defined and commissioned defines who is treated in mainstream oral healthcare.**
Political and policy landscape within which the system is located.	**Influences such as funding cuts and lack of remuneration for prevention impact system dynamics between extremes and mainstreams.**
(2) Navigating the System	
Desired/required journey through the system.	**The oral health treatment pathway someone takes maybe common vs less common thus uncovering extreme/mainstream pathways.**
Frequency of direct interaction with the system.	**Regularity and consistency of engagement with oral health services, including routine dental check-ups and preventive visits.**
Resources needed from system.	**Both tangible (e.g., facilities, equipment) and intangible (e.g., time, information, support) resources required from the oral health system to meet individual oral health needs.**
(3) Individual Perspectives & Experiences	
Social connections.	**Connections with communities and their attitudes and behaviours towards oral**

	health.
Beliefs about system.	Trust in providers, perceived efficacy of treatments, and cultural beliefs influencing oral health practices.
Previous experiences of the system.	Significantly positive or negative past interactions with oral health services or experiences of oral health problems/disease.
System literacy.	Ability to comprehend and apply oral health information, navigate the system, and make informed decisions about oral care.

Table 3: Initial dimensions for identifying extremes in complex systems.

6. Conclusion

This article outlines critical and systemic perspectives on extreme users, drawing insights from a study focused on inclusive oral health systems. The critical perspectives presented reveal: inherent biases in identification and prioritisation, normative assumptions, linguistic challenges, dangers of categorical thinking, and the oversimplification of complexity and intersectionality. Systemic perspectives emphasise the role of the system itself in shaping extremes, the impact of different narratives, and the recognition of a plurality of 'mainstreams' within a system. The article concludes by proposing dimensions for identifying extremes in complex systems over 3 levels: system context (goal of the system, system-defined boundaries, political landscape), navigating the system (desired/required journey, resources needed, frequency of interaction) individual

perspectives and experiences (beliefs about the system, previous experiences, system literacy, social connections).

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Cara Shaw

**Design Researcher on 'SMART Suit' project.
CTO at The Accessibility Institute.
PhD Researcher at the University of Liverpool.**

Cara Shaw is an Inclusive Designer and PhD Researcher who has designed and developed a variety of healthcare and mobility products, from all-terrain wheelchairs and evolvable walking aids to smart exoskeletons and rehabilitation devices. Her work has been recognised by over 15 design awards and her research has been As well as hands-on design and engineering work, Cara has led design research, ethnographic studies and usability trials for a range of companies, start-ups and charity sector organisations internationally.

Cara currently works as a design researcher on the development of an upper-body exosuit for children and young people with progressive neuromuscular diseases. She is also Chief Technology Officer at The Accessibility Institute in Kenya, where she directs and manages the design and development of user-centred assistive technology and mobility products, primarily to support people living in poverty in low-resource settings.

ISSN: 2582-8304

Advancing Inclusive Design in the Context of Paediatric Mobility; Six Key Research Studies and a Critical Implementation Strategy

Cara Shaw

Abstract

This paper reflects on a journey of design research through the field of inclusive paediatric mobility (IPM), sharing key insights, transformative approaches and design frameworks to support researchers and practitioners in the transition towards a more desirable future state for IPM design. This is presented through the introduction and review of six distinct publications which collectively summarise key learnings and findings from the author's past few years as a design researcher in the field. It reflects not only a series of interrelated studies but a coherent story of discovery, progression and the continuous endeavour to improve and advance the field of inclusive design. In this paper, particular attention is given to the roles of narratives, child-centred design approaches, children's rights and design justice principles; insights from this paper are thus applicable and pertinent beyond the core context of IPM and could be of value to those working in the broader realms of design research and design practice. Following a guided tour through each of the publications, the disconnection and tensions between design research and design practice are acknowledged and an implementation strategy for translating research insights into real world design projects is proposed.

Keywords: ***Inclusive Design, Paediatric Mobility, Narratives, Children's Rights, Design Justice, Impact.***

Introduction

This paper firstly curates a progressive body of research traversing the field of inclusive paediatric mobility (IPM) design, and secondly offers five practical considerations for implementing the research to create tangible impact through design practice. IPM design is the application of an inclusive design approach to create mobility interventions such as wheelchairs, walking aids and exoskeletons, with the fundamental goal of optimising the experience of childhood (Shaw & Nickpour, 2021). Rooted within the wider field of Inclusive Design, IPM design draws heavily from the areas of Design for Disability, Child-centred Design, Mobility Design and Design Research; it is rich with technological, sociocultural and commercial considerations and inherits contradictory and permutable opinions and knowledge from a variety of disciplines, stakeholders and subject areas. The field of IPM design has witnessed a lack of both innovation and critical design in the past half century (Feldner et al., 2016; Shaw & Nickpour, 2021). The overarching problems that exist within IPM design are ill-defined, complex, and are reframed whenever societal narratives evolve (Venditti et al., 2017). Access to appropriate IPM devices varies across the world but overall it remains a neglected area of design, meaning young people with a mobility impairment have been physically, emotionally and psychosocially impacted for generations. Beyond mobility, IPM designs can define the limits of a child’s participation and social interactions, their access to education, and the trajectory and overall quality of their life. Ultimately, it is possible for IPM design to change the lives of these young people for the better, which is precisely what this research journey set out to achieve.

By providing a guided tour through each of the six interconnected publications, this paper aims to summarise key findings, shed

light on new approaches and offer practical considerations for translating these into practice to encourage child-centred innovation and more critical design in the field of IPM. Commencing with a mapping review spanning five decades (Shaw & Nickpour, 2021), the historical evolution of designerly ways in the field of IPM is meticulously examined across theoretical, methodological, empirical, and interventional contributions to reveal key knowledge gaps and opportunities. The lens of Children's Rights is adopted to establish priorities for addressing the identified opportunities, building upon five key 'designerly ways' to advocate for the active integration of children's rights into IPM design (Shaw & Nickpour, 2023a). The exploration of child-centred framing in IPM design led to the interdisciplinary creation of a child-centred framework for analysing young people's design ideas (Shaw, Bernardi & Nickpour, 2022), to elevate their aspirations and centre their narratives in the IPM design and development process. This inspired a piece of theory-building research to position Design as an agent of narratives (Shaw & Nickpour, 2022) resulting in the creation of a conceptual framework to acknowledge, negotiate and embed narratives in design. To further understand how lived experience narratives could inform IPM design, young wheelchair users' personal mobility narratives are captured and interrogated (Shaw & Nickpour, 2023b) using the conceptual framework to uncover dominant, alternative and counter narrative themes that transcend mere mobility, embracing identity, resilience, and societal inclusion. The research journey culminates in an expansive view of design's role, advocating for the proactive incorporation of narratives throughout and beyond the design process (Shaw & Nickpour, 2023c). This last phase of research emphasises the importance of narratives not only as reflective elements but as a dynamic medium capable of challenging

stereotypes, democratising participation, and guiding systemic transitions. Collectively, these six publications narrate a transformative trajectory, steering the field of inclusive paediatric mobility design towards a future which centres empathy, inclusivity, and a profound understanding of the nuanced narratives that shape the lives of young individuals with mobility challenges.

Research Approach

Each of these publications were written to document the result of studies undertaken as part of the author’s doctoral research. The decision to publish these studies was made with the aim of disseminating research findings to reach the intended audiences via relevant journals, conferences and book chapters to optimise the impact of the research contributions. A broad range of qualitative and quantitative data collection methods and analysis techniques were utilised across the studies, each of which will be summarised in the following section.

Six Key Research Studies

The six publications presented in Table 1 collectively convey the essence of this research journey whilst individually contributing in its own way towards the overarching goal of advancing inclusive design in the context of paediatric mobility. The publications represent a critical and reflective body of work striving to advance designerly ways in IPM through contributing various frameworks and insights primarily focused around the core themes of children's rights, child-centred design, the role of narratives in design, exploration of lived experiences, systemic change and transformative impact.

Table 1. Details of the six key research studies.

#	TITLE
1	A Framework for Transitioning Designerly Ways; Interrogating 50 Years of Inclusive Design for Paediatric Mobility.
2	Design as an Agent of Children's Rights? Inclusive Mobility Design for Children with Disabilities.
3	Child-centred Framing Through Design Research: A Framework For Analysing Children's 'Dream Wheelchair' Designs to Elicit Meaning and Elevate Their Voice.
4	Design as an Agent of Narratives: A Conceptual Framework and a First Exploration in the Context of Inclusive Paediatric Mobility Design.
5	Embedding and Embodying Narratives in the Collaborative Development of Life-changing Healthcare Technologies.
6	Phenomenological Analysis of Young Wheelchair Users' Narratives to Improve Understanding of Meaning.

1. A Framework for Transitioning Designerly Ways; Interrogating 50 Years of Inclusive Design for Paediatric Mobility

This research journey began with a foundational study delving into the historical landscape of inclusive design for paediatric mobility, setting the stage for subsequent investigations. The goal was to reflect on the evolution of 'designerly ways' in the field over five decades (1970 to 2020) and identify gaps in knowledge and opportunities to improve by chronologically mapping IPM design contributions across Theoretical, Methodological,

Empirical, and Interventional categories. A Reflection-for-Transition framework of Designerly Ways was developed to identify existing and alternative designerly ways, through categorising key insights from the mapping review. The framework consists of five interrelated dimensions, including Designerly: Investigations, Processes, Contributions, Collaborations, and Contexts. Following an in-depth critical and reflective review of the field, alternative designerly ways- were proposed which included the following:

- **Designerly investigations should shift from capturing underlying requirements to first exploring high-level narratives and imaginaries.**
- **Designerly processes should reprioritise focus from problem-solving to problem-framing.**
- **Designerly contributions should move beyond being interventionally-focused to attend more rigorously to documenting and sharing theories, methodologies and empirical research, to build a body of knowledge.**
- **Designerly collaborations should transition from multidisciplinary involvement towards transdisciplinary design teams.**
- **Designerly contexts should progress from adopting immediate perspectives of time and place to exploring extended perspectives.**

It is suggested that these proposed alternative designerly ways could help the transition towards a more desirable long-term future for IPM design. (Shaw & Nickpour, 2021).

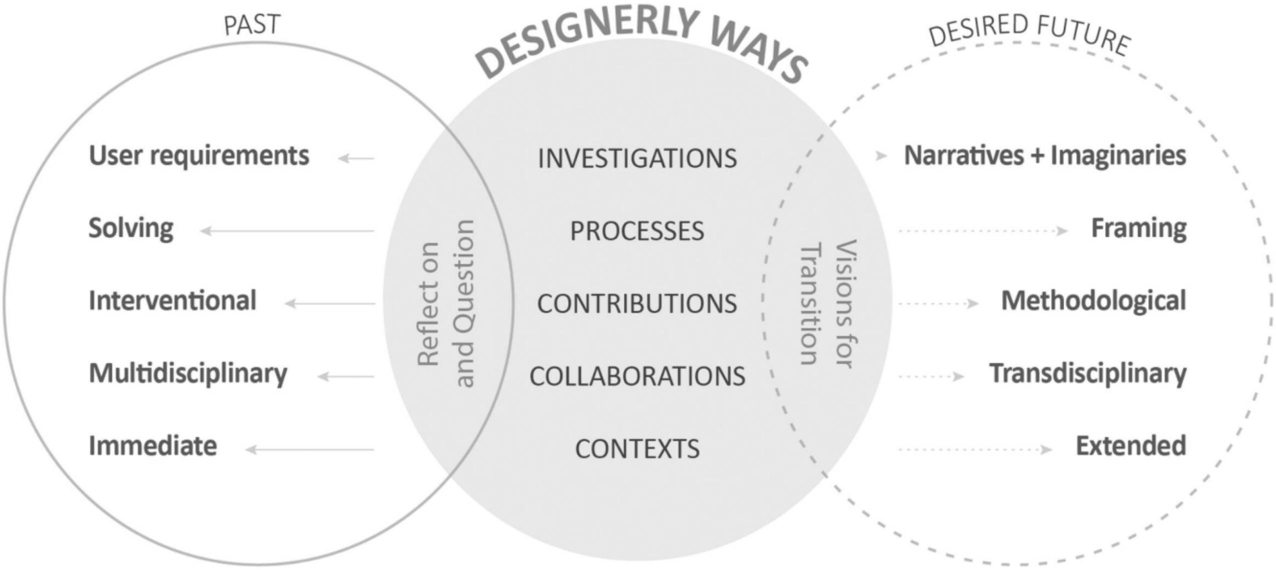

Figure 1. Reflection-for-Transition framework of Designerly Ways; 50 years of IPM Design.

2. Design as an Agent of Children's Rights? Inclusive Mobility Design for Children with Disabilities

Building upon this historical context and the five key 'designerly ways', this study positioned design as an agent of Children's Rights and elucidate the role of design in acknowledging, integrating and facilitating the rights of children with disabilities, and advocating for the active integration of children's rights into IPM design (Shaw & Nickpour, 2023a). The study aimed to bridge theoretical frameworks of inclusive design with the practical implications for children's rights, laying the groundwork for a more holistic understanding whilst drawing on core topics such as design justice (Costanza-Chock, 2020) and design ethics (Felton et al., 2012). Two key directions are outlined regarding the transitioning and prioritisation of designerly ways, to help optimise Design as an agent of children’s rights in IPM design. These include (1) establish a more rigorous framing process within designerly investigations which pays specific attention to

capturing narratives and (2) optimise a child-centred approach to designerly processes and collaborations.

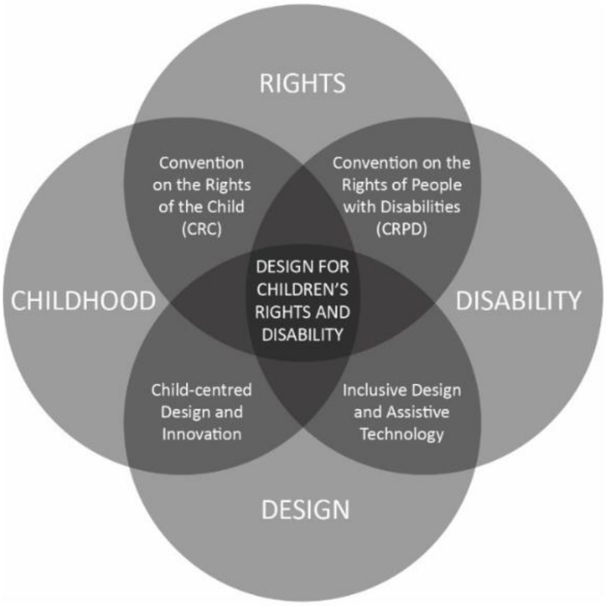

Figure 2. The relationship between Design and disabled children's Rights.

3. Child-centred Framing Through Design Research: A Framework for Analysing Children's 'Dream Wheelchair' Designs to Elicit Meaning and Elevate Their Voice

Guided by the previously prioritised child-centred design approach, the journey progressed to "Child-centred Framing Through Design Research: A Framework for Analysing Children's 'Dream Wheelchair' Designs to Elicit Meaning and Elevate Their Voice" (Shaw, Bernardi & Nickpour, 2022). This research took a closer look at children's perceptions and aspirations regarding mobility devices and aimed to capture their personal mobility narratives through visual and written mediums. A child-centred design analysis framework is developed in an interdisciplinary manner, comprising four dimensions including Child, Content, Context and Format. It is used as a vehicle to analyse 130 dream wheelchair designs by children and uncover insights into children's individual and collective mobility narratives, values and

requirements. Themes from the analysis are explored through a qualitative interdisciplinary lens to understand the nature of children's lived experiences and amplify children's voices in a way that could be used to frame problems from lived experience perspectives and meaningfully inform the design process.

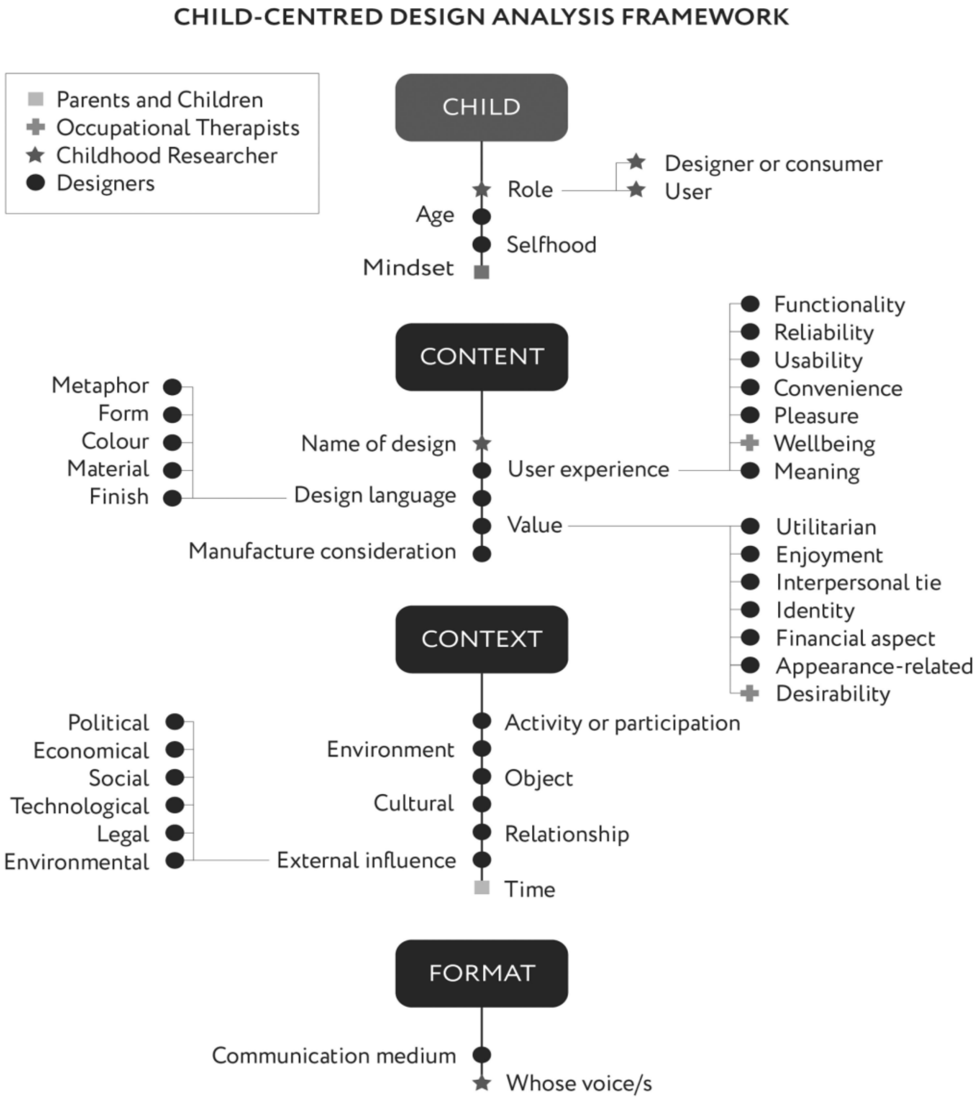

Figure 3. Child-centred design analysis framework.

4. Design as an agent of Narratives: A conceptual framework and a first exploration in the context of inclusive paediatric mobility design

With the intention of further exploring how narratives can be used in design to frame or reframe individual and collective

experiences, sensations and situations (Shahar & Ventura, 2023), this study set out to position design as an agent of narratives. Narratives are inherently embedded and embodied through design but there is urgent need to challenge and advance this role from perpetuating dominant narratives, to becoming a proactive, critical and generative agent responsible for uncovering, interrogating, speculating, and scaling a diversity and plurality of narrative 'sources' and 'statuses'. In this study a 'Narrative Matrix' is outlined and a Conceptual Framework is proposed which frames design as an agent of narratives through three strategic narrative stages:

1. **Acknowledgement and capture.**
2. **Negotiation and speculation.**
3. **Embedding and scaling.**

The implications and possibilities for incorporating narratives in design and innovation processes are then discussed, covering the potential to proactively amplify marginalised voices and bring about systemic change and transformative impact (Shaw & Nickpour, 2022).

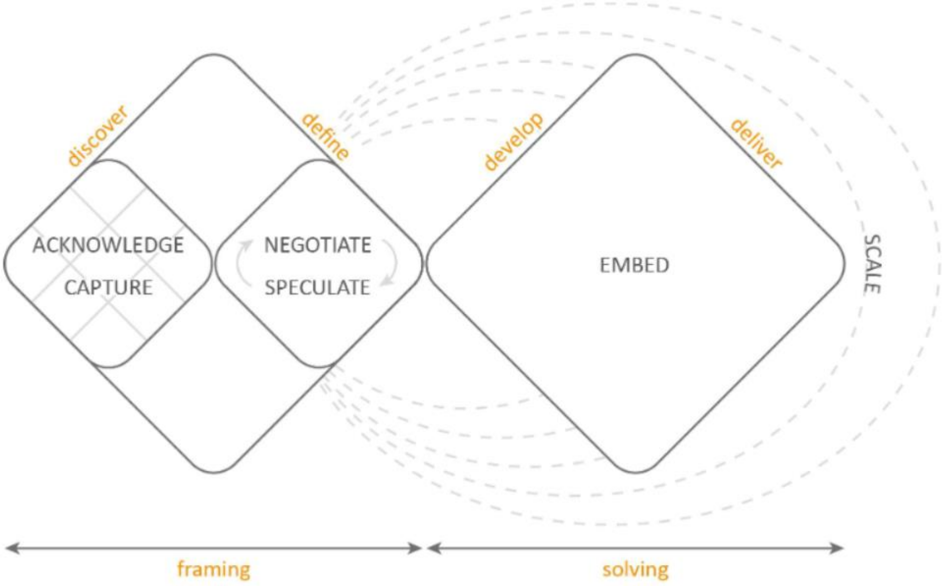

Figure 4. Conceptual framework for design as an agent of narratives.

5. Illuminating Narratives of Young Wheelchair Users: Lived Experience Insights for Framing Child-Centred Inclusive Mobility Design

Seeking deeper insights into the lived experiences of young people with IPM interventions, this qualitative study set out to uncover and interrogate the narratives of nine young wheelchair users. In-depth narrative interviews are conducted and analysed to unveil five high-level narrative themes including: Independence, Freedom and Choice Beyond Mobility; Social Inclusion and Support Networks; Identity, Customisation and Self-Expression; Accessibility and Adaptations; and Resilience and Determination. An interpretive phenomenological analysis was then conducted to identify archetypal dominant, counter and alternative narratives that exist around each theme. The study elucidates the complexity, duality and dynamicity of end-user narratives and highlights how mobility devices can act as vessels for narratives which transcend the primary concept of mobility, encompassing a deeper sense of identity and selfhood, enriched with values, feelings, and opinions related to various areas of life. As well as offering insights into the lived experiences of young wheelchair users, the narratives identified through this study could be adopted in IPM design practice to inform sense making and opportunity framing processes, to ultimately create more meaningful child-centred solutions and empower users (Shaw & Nickpour, 2023b).

6. Embedding and Embodying Narratives in the Collaborative Development of Life-changing Healthcare Technologies

Recognizing the transformative power of narratives, this final study in the series focuses on the latter two stages of the 'Design as an Agent of Narratives' conceptual framework i.e., establishing which narratives to include in the design and exploring how to incorporate them. A real world IPM design project is used in this case study, to capture project stakeholders' thoughts and expectations on which end-user narratives to include as well as how they could and should be embedded within or scaled beyond the project-specific design process. The study reveals the most commonly suggested level and phase of the project to incorporate narratives was the 'Product Requirement' level in the 'Concept' phase of the design process, where activities such as documenting a user requirements specification typically take place. This highlighted the need for future research to focus on exploring how best to package narratives in a way that they can be appropriately embedded within existing design documentation formats (Shaw & Nickpour, 2023c).

A Critical Implementation Strategy

As is typical for design research (Rodgers & Yee, 2023), the aforementioned studies focused primarily on capturing insights, generating knowledge and sensemaking. It is essential that the outcomes of this research can now be translated and utilised within design practice in order to deliver tangible results and ultimately achieve real world impact as intended. The disconnections and tensions which exist between design research and design practice are widely acknowledged (Centazzo & Pope, 2023), and often make it challenging for design research to achieve its intended impact (Shaw & Nickpour, 2024). This section of the paper puts forward considerations for addressing some of the key tensions, to facilitate application of the design research outcomes in practice.

Tensions relating to the practical implementation of design research presented in this paper centre around A. exploring and embedding narratives in the design process; B. facilitating child-centred collaborations; and C. transforming qualitative insights into utilisable working formats for design practice. The top five identified tensions are expanded on and discussed in Table 2, offering a critical implementation strategy which aims to support design practitioners to adopt them in real-world design projects.

Table 2. Critical implementation strategy addressing tensions between research and practice.

Tension	Applying Design Research in Design Practice
Mindset towards designerly investigations	**While design practitioners tend to use problem solving and idea generation as a way of building understanding in the early stages of designerly investigations, it is suggested that in-depth problem framing and sensemaking should instead be prioritised and addressed first. Specifically, the acknowledgement and capture of end-user narratives should be carried out at the start of the design process to ensure any resulting insights contribute meaningfully to frame subsequent problem-solving efforts and ultimately deliver more appropriate, impactful, and user-centred design outcomes.**

Recruiting for child-centred participation	**While design practitioners typically outline participant recruitment inclusion criteria based on characteristics matching those of their 'target user' as outlined in a design specification or similar document, design research advocates for an equity-based approach to participant recruitment, considering diverse factors like their gender, race, socioeconomic status, and location. The use of an inclusive recruitment framework such as the ICER (Shaw & Nickpour, 2023d) may increase the time and effort required for participant recruitment due to added layers of selection criteria, but it can ensure diverse participant representation and mitigate the risk of insights being biased or not fully representative.**
Documenting insights and requirements	**While design practitioners acknowledge the value of qualitative insights and sensemaking activities, the first formal piece of traceable documentation they produce is typically a user requirement specification, an intended use document and/or a design requirements specification - each of which outline and quantify various measurable requirements, constraints and specifications that the design should conform to. The quantitative nature of these rigid and regulated documentation formats means that many of the highly qualitative insights initially collected struggle to translate well, and risk being lost after this point in the design process. An alternative documentation format such as a 'user requirements insights' file with assigned codes or numbers to each entry can be utilised to ensure these nuanced insights which are vital for understanding users' lived experiences are formally recorded and thus remain traceable throughout the design process.**

Timeframes and pace	While design practitioners generally take a fast-paced approach to deliver against predetermined project timelines, design researchers, and particularly those in academia, tend to take a slower pace to ensure rigorous capture of insights with enough depth to deliver long-term meaningful impact. This can involve time-consuming research activities, often requiring ethical approval, participant recruitment and planning logistics - such activities rely on other people and thus the timescale to carry them out can be difficult to control. Since design practitioners often face immediate project deadlines, it is easy for such research activities to be rushed or emitted which risks missing vital insights and cultivating superficial collaboration. The timeframes of design research can be managed to better suit design practice without having to compromise rigour or depth by planning and preparing methodological requirements, establishing genuine collaborations ahead of time and being flexible to engage with participants around their own schedules.

Nature of stakeholder collaboration	While design practitioners traditionally lead the decision making process, design research proposes that a more holistic and democratic decision-making approach is taken to foster shared problem-solving, co-creation, and innovation. This requires moving away from transactional collaborations and instead establishing open communication and mutual respect between designers and a broad range of stakeholders to integrate diverse expertise as well as integrate the voices of users throughout the design process. Addressing root causes relating to resource limitations, communication challenges, tight schedules and the inwards-facing culture of some design organisations are just a few ways design practitioners could establish more meaningful transdisciplinary collaborations. Failing this, an alternative option could be to embed and embody stakeholder narratives throughout the design process (Shaw & Nickpour, 2023).

CONCLUSION

This body of research reflects a story of progression, discovery, and the continuous endeavour to bring about positive change in the realm of child-centred inclusive design. Key takeaways from the six studies presented in this paper include an urgency to transition designerly ways, the need for child-centred framing, the importance of children's rights in IPM design, and the recognition of design as an agent of narratives. These insights extend beyond the field of inclusive paediatric mobility design, offering broader applicability to design research and practice.

The proposed implementation strategy introduced in this paper acts as a blueprint for design practitioners to bridge the gap between research findings and tangible impact, ensuring that the insights presented in this body of research transcend the realm of

academia to manifest in real-world design projects. As the design landscape evolves, this research aims to pave the way for a more inclusive, child-centred, and impactful future for the field of IPM design.

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Andrew Tibbles

Designer-in-Residence, Marie Curie Liverpool.
PhD Researcher, the University of Liverpool.

Andrew Tibbles is a speculative designer and a PhD researcher with a fascination for the consequences of new and emerging technologies on individuals, collectives and societies. His background is in product design and he made a career in makerspaces, creating, experimenting and teaching emerging modern manufacturing techniques and machines across the UK.

What began as a pragmatic honour's year project towards death, dying and beyond, became a source of constant curiosity and is now part of his PhD research in collaboration with Marie Curie Hospice Liverpool; exploring how, why and should technology and artificial Intelligence play a role in the future of hospice care. And what many forms those technologies could take to strive towards a 'good death' in the modern age. Andrew's PhD is funded by Doctoral Network in AI for Future Digital Health.

ISSN: 2582-8304

Influences in Eliciting Authentic Answers in Design Inquiry and Imagination: through the lens of participatory design workshops

Andrew Tibbles

Abstract

Observations from participatory design workshops have resulted in a personal scepticism on the authenticity of participant contributions. This may be due to a participant being unable to express their lived experience or simply they have not examined them critically before the workshop. Secondly, the social desirability bias present within a group dynamic is prevalent in these workshops, described from the perspective of the facilitator and participant. Participatory design workshops have unconscious values present in their tools which may need to be consciously chosen to obtain authentic contributions at the risk of biased results. Group dynamics in participatory workshops may be used to reinforce dominant narratives, or as a way to evidence and challenge them.

Keyword

Participatory Design Workshops, Authenticity, Rigour.

Introduction

Participatory Design and its branches such as the many forms of co-design are becoming increasingly popular in and outside of the field of design for their ethical underpinnings of involving those who are being designed for in the process. This is especially relevant for those who are socially marginalised where a non-marginalised designer simply would not know the barriers they

face in life. So, it cannot be enough to simply involve a person in participatory design; they must also be, to the best extent we can, understood. To begin to understand another’s experiences we cannot perform simple tokenism in participatory design, there must be a level of depth to the engagement which allows participants to give reliable and authentic contributions.

As design shifts to tackling more societal level and complex systemic problems with participatory methods, it requires a broad representation of stakeholders and interdisciplinary teams to design and coordinate together. How much does a designer influence reflective practice through the tools of their craft and how authentic can contributions be in a group setting with those who hold a position of power to change systems? This does not necessarily refer to the people in a position of power overriding or not listening and engaging with the stakeholders, but it is true that those able to make change may not feel free to express their insights in case there is a loss of trust from those they wish to help. For instance, a healthcare professional may not suggest, in a group setting with stakeholders, that some patients' lives were not worth continuing because of the quality of life they are likely to have after a specific life-saving treatment, despite their experiences.

Can participatory design elicit authentic answers?

This article is not intended to be an authoritative answer to this question but a discussion of the methods of participatory design with these points in mind. These have come from professional experience of using various methods to answer difficult and intimate questions that may well be answered in another discipline, but I have yet to find it for the field of design.

What is participatory design?

As a quick definition, participatory design methodology sees knowledge-making as occurring through the interaction among designers and stakeholders, practices, and artefacts (Spinuzzi, 2005). Many participatory tools and techniques are now available to design researchers to apply to different contexts and populations (Sanders et al., 2010).

What do we mean by authentic answers?

Getting to know the unknown

In this case, authentic answers are when participants of research or design express the genuine reality or desire of an experience. Why doesn't this happen? Sometimes the person may not have the ability to express themselves fully or articulately, a strong potential with any form of language. Other times, the question is asking about experiences and emotions they themselves do not know because they may not have the capacity to understand and articulate the experience or ever given time to examine it. This is what Marc Steen quoting John Dewy describes as primary experiences of "gross, macroscopic, crude subject-matters'' (i.e., experiences that come "as the result of a minimum of incidental reflection") which then can be developed through reflective practices resulting in secondary experiences of "refined, derived objects of reflection" (i.e., experiences "in consequence of continued and regulated reflective inquiry." (Steen, 2013)

Participatory design can be considered a reflective practice of inquiry and imagination. However, the process is not without influence. Designers understand that designed elements such as graphics, objects, interactions and environments hold perceived

values and affordances both in their materials and culturally. Participatory design is a combination of communication methods between stakeholders to come to a joint decision. There is a minimal amount of materials required for this, most commonly a large blank canvas (e.g. a wall or A2 paper), a mark maker (e.g. marker pen or digitally a keyboard or pen pad), potentially smaller interchangeable elements (e.g. post-it notes) and a facilitator - this is so a collective thought process and the decision can be reached on a reasonable human scale. These materials used are not usually considered inherently valuable and are used with an iterative process towards valued understanding. However, I argue that with other materials with different affordances and values, you would receive a different thought process and therefore collective decision. For example, if the large canvas was a courthouse wall, our mark maker; chisels, and our smaller interchangeable elements; wood blocks. This is an extreme scenario but enough to illustrate my point that designed elements may influence research outcomes.

An element emitted from the example that may be able to both mediate or exacerbate some of these tensions is the facilitator. In a workshop, a facilitator aims to be neutral in their approach, so as not to influence decision-making in a particular direction, but they are not infallible. However, in a personal account of myself facilitating an art performance piece guiding participants to answer an uncomfortable and intimate question, I remain neutral in my question and tone but my environment and myself are used as tools of influence.

A personal account of getting to know the unknown

This topic of discovering authentic answers goes back to my undergraduate studies. My final year project was The Aquatic

Grave, an underwater burial system in the waters surrounding the islands of Scotland. This project was conceived for ecological reasons and to make sound design decisions, I had to talk to a lot of experts outside of my field. From anthropology to marine biology, contributed to the final grave outcome which is deceptively simple, low-grade steel boxes with some small holes cut in the bottom and top.

As a form of thank you for helping me, I proposed that I put their names on the graves. I know what you're thinking, "Wow! What an amazing thank you!" but hold your applause. As part of the service, I had designed a way that visitors could go to the grave in a small boat and listen to what the dearly departed had to say, this required the dearly undeparted to reflect on what they'd like visitors to their grave to hear and I had to record it. The interaction of me recording what they'd want people to hear when they had passed was, to me, fascinating.

I remember those who were already comfortable with public speaking were easily able to address the world with who they were and their advice or philosophy, others simply couldn't talk about how they were feeling in front of me but became overwhelmed in private without guidance. I distinctly remember a lecturer at the time, it was just me and him in the department office, and his voice note addressed his children and wife. It was profoundly personal, spoken with beautiful eloquence while tears formed in his eyes. I don't know if this was something he had thought about beforehand or wrote this speech out, but it was moving.

I experimented sparsely for a number of years for ways to capture the clarity and intimacy he was able to summon, seemingly at the drop of a hat, and to eventually guide others through knowing the unknown.

My first failed attempt was during a death cafe, these are open forums where people can comfortably and confidently speak about death and dying. It isn’t typical to have themes or the facilitator to bring a task, but I thought it was a good opportunity to experiment. I asked the group the same question, what would you like people to hear after you die? I rolled out a large piece of paper and gave out pens. This resulted in tense joke-making and people creating quips and one-liners to diffuse the unease and to gain a chuckle. Surface-level responses that I don’t believe given a chance they would honestly want loved ones to hear, but this is also my bias creeping in. Famously, the comedian Spike Milligan’s grave has an Irish saying on it "Duirt mé leat go raibh mé breoite" translating to English as "I told you I was ill", so perhaps a zinger would be enough, but I wanted to search for more nourishing responses.

My second failed attempt was while I was working for a creative office working space and so had access to willing victims. I decided to try one-on-one style in a private space. The place still had some rubble on the floor, a cold fluorescent tube light and the sound of a flushing toilet from the floor above was very pronounced in the pipes. I scraped a table in from anywhere I could find one along with some uncomfortable wooden chairs. I situated myself and interacted with the person differently each time, sitting in silence and keeping comfortable eye contact, leaving the room after pressing record, and being conversational, but there was a marked difference when I balanced all three. I set up a screen between me and the person. I asked simple guiding questions, being more formal than conversational. They knew I was there but they couldn’t see me so they wouldn’t look to me

for reassurance or try to read my body language. The first screen was just a sheet of ply I found. The person I was interviewing said they'd like to be able to see some part of me so they didn't feel like I had left the room. So I made a 'confession' style screen. Cutting a pattern into the wood that would let the person know I was there, but they were not able to see my face or read my expression.

I had a vision of what I wanted to do next with it but did not find the time or resources to realise it. A few years later, an opportunity arose to further the experiment but as an artist performance piece this time. The environment was an old semi-circle operating theatre in Edinburgh with high ceilings and rows of stepped bench seating. The set-up was a tall white sheet of fabric that, at a guess would say reached the ceiling at four metres high, spotlights pointed onto the sheet, and I lit tea lights around the room with incense. I would sit on the side of the sheet with the straight wall to my back, and my participants would sit in the open circle. The chairs were wood with a deep red leather cushion, the reality of the situation was that if it weren't for the sheet between us, we would be sitting uncomfortably close to each other (Figure 1). To play my performance, I shaved my head, went barefoot and donned a black robe, leaning into the idea of the religious authority figure of the confession booth (Figure 2).

Figure 1. (left) Im'mortal art piece performance set up.
Figure 2. (right) me in situation and in costume.

Rather than my opening question being, "What would you like to be heard after you've died?" I asked if they wanted to be immortal, and most answered no, and then I would respond that at some point they did in fact wish to die, which, granted, is an odd logic or at least an odd way to put it. I continued to ask; how would they imagine their death, if they believed in an afterlife, if they could create their own afterlife what would it be, if not, I asked when they last felt serene and we would use this memory, from the afterlife they had received an opportunity to speak to those who remained, who did they see and what would they want to say to them. Remaining silent for a little longer than I would usually be comfortable with and them not being able to see this, I believe allowed for turning points and a deeper analysis of their own emotions and thoughts. The answers were surprising, they would often be analytical reflection and introspection, while as we

moved through the questions, they were more fluid and almost instinctual, surprising the participant themselves by how confident they felt about their answer. I know people felt deeply about the performance piece as many did cry and thank me afterwards - sometimes with a strong hug. But can I say that these were particularly authentic answers or did I provoke an emotional response by influencing their reflective practice? Although in this case, we were not designing a thing through a method of participatory design, we were crafting a sentiment together through reflective practice and the findings and experiences apply to participatory design practice and tools.

Hiding the known for the desired

Participatory design is conducted with the belief that contexts and situations can be improved with communication and collaboration with stakeholders. This assumes that people will naturally give forth honest information through inquiry, however, participants may know how they feel but wish not to express it due to how they may be perceived by others, this is described as social desirability bias, which I've found is not a common consideration for design research. In Nicole Bergen and Ronald Labonté's paper "Everything Is Perfect, and We Have No Problems": Detecting and Limiting Social Desirability Bias in Qualitative Research, their introduction states several situations where social desirability bias appears and the problems that arise from it. These situations can all be something present within a participatory design workshop such as; in sensitive or controversial topics, situations where there are widely accepted attitudes, behaviours, or norms, and individual characteristics such as social (and I will add organisational) position, gender, and personality traits (Bergen &

Labonté, 2020). This can lead to research concluding a false conclusion and reinforcing dominant narratives.

A personal account of hiding the known for the desired

I have already mentioned these experiences as my first failed experiment, and it was certainly present in other experiments I did. The first failed experiment was the group of participants who did not wish to engage in reflective practice and to be vulnerable in front of strangers, and opted for a group-pleasing answer. This is a textbook example, which I understand the desire to do as a confessed people pleaser. Secondly, as an interviewer, my participants would look to me for reassurance that this is what I was looking for from them hence when I went behind a screen and became present unseen, participants would open up or allow a pause for further thought to develop. In these instances, participants were trying to appease me while I was questioning them.

I have been a facilitator of group workshops for several years, mostly these have been educational, but there have been many participatory design workshops, in which I have played both roles of facilitator and participant. There’s no one fluid account or story from which to draw here, but a series of incidents in different locations, under different settings, and aiming for different outcomes.

As a facilitator

My most recent ventures have been examining future hospice care and the role of technology, typically robots, within them. I find this bias much more difficult to spot because the answers themselves feel genuine. There has been a common theme throughout my recent workshops where I have been asking

groups of stakeholders to imagine desirable features of hospice care with three users and how technology can support each of their needs; the patient, the family, and the staff.

Increasingly, healthcare services are becoming, if not already, patient-centred in their service approach. Hospice models may also subscribe and say that they base their practice on this thinking, but through my personal experience of being in a hospice studying the system, it goes beyond patient-centred care. Hospice care systematically assesses and cares for the state of those close to the patient, sometimes also the patient's carer, and their health physically and mentally. Two of the three users mentioned are in practice accounted for and are two different but linked centres of care. It's when we came to the point in the workshops when we asked what the staff found desirable and how they would like to be supported in future that the bias potentially crept in.

Hospice staff work hard for what is increasingly unsatisfactory pay. It is a difficult job physically and emotionally, and you need genuine compassion for human beings to be able to perform it. From passing comments and interviews, the majority of medical staff prefer hospice work to hospital work because you are granted the opportunity to care for the person, the human, and not simply the body. This is something that they find desirable in their work. Consistently throughout the workshops, however, a familiar dominant narrative appeared; that the technological interventions they imagined would simply replace them, which was bizarre considering up until this workshop this was a huge fear for both the staff and the patients that they would lose human connection, which was considered vital and highly desired for their work. In our participatory workshop, they imagined they

were workers and they were here to do a job not to be fulfilled or have their desires met.

Perhaps by wishing to be seen as caring, potentially selfless or professionally patient-centred, they omitted how they felt they fulfilled the role and how they could be supported. It is worth noting that there was not one level of organisational hierarchy in the workshop, so when imagining themselves in the situation, they didn’t want to bring up anything that sounded like a complaint or criticism to the managerial level. This is of course all speculative and I can only assume why during the workshops, staff wrote themselves out of a desirable future for hospice care.

As a participant

Because of my professional background and my personality type, when I have been involved as a participant in participatory design workshops, I’ve had to be very conscious of not becoming a defacto facilitator. As I empathise with the goals of the researcher, I know how I would like participants to be involved in a workshop and dead-stare-silence is excruciating, but as I’ve tried to break the silence by asking others questions, input, or pitch ideas to help get things rolling, my contributions sometimes end up being the majority of it. Other participants were quite happy to relinquish their input to someone with seemingly more enthusiasm. The conundrum also lies on the other side of this line - by keeping quiet and sitting in the uncomfortable silence waiting for someone else to take the lead, I hide input or disengage from a potentially valuable reflective practice for others. In both these cases as a participant, group dynamics can quickly form and the potential for groupthink grows.

In defence of participatory design from my experiences, these have been short or day workshops and not recurring participatory

design development over weeks or months. Which over a lengthier period may allow for participants to open up, reflect further and respond more authentically. During a longer period, using participatory design problems and solutions can co-evolve, simultaneously being explored, developed and evaluated in an iterative process.

Conclusion

Summarising the above and two questions to consider about the rigour of design knowledge building in the area of participatory design.

Design values present in the creative tools and environments that participatory design uses, along with the presence of a facilitator, have an impact on the reflective practices of individuals. However, do we aim to minimise these for authentic answers to emerge on their own, if they can, or do we create practices and tools with values embedded that may encourage and guide participants towards authentic answers and risk bias results?

The group setting of participatory design can be a hindrance, at least for short-term interventions, as group dynamics if not already present, form quickly and there is no time to undo or reflect further on those dominant narratives. So, are short-term participatory workshops as a form of design inquiry or imagination reinforcing potentially harmful narratives or a way to identify and challenge?

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Luka Kille-Speckter

Installation design & third sector consultant.
Design Researcher at Mersey Care LifeRooms.
Visiting Lecturer at HDM, Stuttgart, Germany.
PhD Researcher at the University of Liverpool.

Luka Kille -Speckter is a lived-experience designer, consultant, PhD researcher and educator. Her mixed background of social science, experience design and inclusive design, Luka combines her expertise with her lived-experience of visual impairment to outline design opportunities and impact.

ISSN: 2582-8304

The Illusion of Inclusion;

Exploring the Paradox of Simulations and Simulation Toolkits in [Inclusive] Design

Luka Kille Speckter

Abstract

Simulation toolkits have become ubiquitous within the design industry, purportedly fostering inclusion by offering a glimpse into diverse lived experiences (Cardolo, C. and Clarkson, J., 2010). This paper critically examines the potential pitfalls of relying on such simulations, questioning whether they inadvertently perpetuate the illusion of inclusion. While the noble intention is to accommodate a broad spectrum of needs, the current limited and singular understanding and application of these tools poses a looming danger of inadvertently upholding an ableist approach, and leading to unintentional exclusion. The research elucidates instances where simulations may go awry, exploring their overarching impact on the communities they aim to represent and their role in shaping prevailing narratives (Silverman, 2015). The paper emphasises the influential power of narratives and delves into their connection with psychosocial inclusion. Introducing a personal dimension, the paper incorporates a brief auto-ethnographic section where the author shares their own experiences with disability simulations. This firsthand account adds depth to the exploration, offering insights into the potential disparities between simulation intent and the nuanced reality of lived experiences. The article adopts a double lens of lived experience and disciplinary expertise to capture insights and

investigate issues and discuss the issues. In conclusion, the paper offers a concise summary of suggestions, serving as a guide for future designers aiming to navigate the complexities of simulation toolkits while genuinely advancing psychosocial inclusion.

Keywords

Simulations Simulation Toolkits, Psychosocial Inclusion/ Exclusion, Narratives of Disability, Lived-Experience.

1. Introduction

Design wields the influential power to shape not only our interactions and behaviour but also the very philosophy of inclusion itself. As a conduit of embodiment and material culture, design plays a pivotal role in moulding numerous human interactions and experiences. Consequently, it can either inherently facilitate accessibility and inclusivity or, conversely, perpetuate exclusivity and inequity ‘by design’.

In the realm of design, a significant shift towards embracing the principles of Equality, Diversity, and Inclusion (EDI) has been taking shape. Alongside this shift, a new array of tools and simulations has emerged. Referred to as simulations/ simulation toolkits, empathy toolkits, or inclusive design toolkits, we will use the term 'simulations/simulation toolkits' in this paper for simplicity.

These simulation toolkits have emerged as instruments to foster inclusivity and create designs that resonate with a broader range of individuals (Cardolo, C. and Clarkson, J., 2010). They come in various forms, such as SimSpecs, gloves simulating arthritis, and even full-body suits that replicate the effects of ageing, to name a few. The underlying intention behind these tools is commendable:

to help designers walk in the shoes of those with different conditions, fostering a more empathetic, inclusive design process (Cardolo, C. and Clarkson, J., 2010). As a result, the field of inclusive design has dedicated significant attention to the study of physical accessibility, functionality, usability, and physical comfort. This focus has been particularly pronounced in relation to two key dimensions: age and physical ability.

However, as with many well-intentioned endeavours, there is a paradox at play. The very tools designed to facilitate understanding and inclusivity may, in certain instances, perpetuate exclusion and inadvertently contribute to an ableist deficit-based narrative (Silverman,2015).

In the pages that follow, we will explore the complex relationship between simulation toolkits and unintended exclusion, examining the intricate dynamics at play, considering both the benefits and pitfalls of their usage. Our goal is not to discourage the use of simulation toolkits, but rather to promote a nuanced understanding of their implications and to propose strategies for their responsible and inclusive application.

2. Mapping the Landscape of Simulation Toolkits

This section serves as a map, guiding us through both the well-trodden paths of widely recognized tools and the uncharted territories of lesser-known simulations and immersive experiences. This paper selectively showcases specific types of simulation toolkits, focusing on age and ability. As a non exhaustive review, it does not cover simulations beyond these categories, such as pregnancy simulations. By surveying this landscape, we aim to gain a deeper understanding of the tools that designers have at their disposal.

2.1 University of Cambridge Gloves and Glasses Simulating Physical Limitations

Image 1.1 University of Cambridge Engineering Design Centre Simulation Gloves and Glasses

Among the most prominent and widely recognized simulation toolkits in the world of design, we find a set of gloves and glasses developed by researchers at the University of Cambridge's Engineering Design Centre (Hosking, Cornish, Bradley, Clarkson, 2015). They are a powerful call to action, imploring designers to reconsider the usability and accessibility of their products (Hosking, Cornish, Bradley, Clarkson, 2015). The underlying intention is to instil a sense of empathy (Cardolo, C. and Clarkson, J., 2010)., encouraging designers to walk in the shoes, or in this case, wear the gloves and glasses, of those struggling with reduced grip ability (e.g arthritis) and reduced vision.

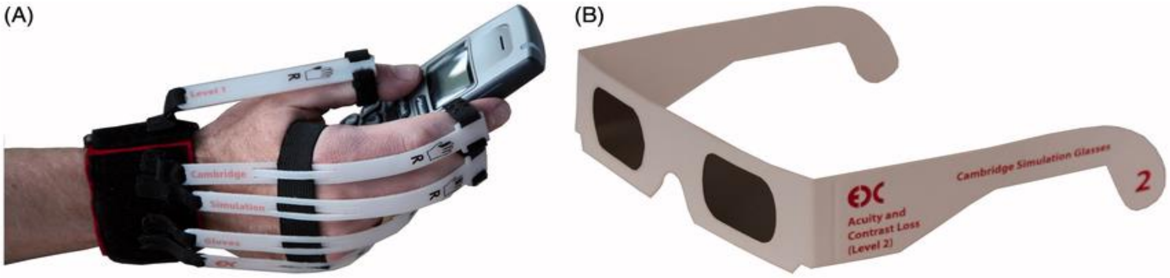

Image 1.2 ***University of Cambridge Engineering Design Centre Simulation Gloves and Glasses***

2.2 University of Cambridge Exclusion Calculator

Offering a quantitative dimension to the pursuit of inclusivity, The Exclusion Calculator serves as a practical and data-driven instrument for designers. This calculator was developed as part of the ID-3 Inclusive Design Consortium run by the Centre for Business Innovation, and is based on UK population data from 1997 (*Cambridge* Engineering Design Centre, 2017). This freely available version of the exclusion calculator allows designers to assess a specific task.

2.3 Age Simulation Tools - GERT and Ford's Third Age Suit

In this example, we will explore two tools simulating age-related impairments: GERT, the Age Simulation Suit, and Ford's Third Age Suit.

Image 1.4: Ford's Third Age Suit - Designing with Seniors in Mind

Similarly, automotive giant Ford has embraced the concept of empathy in design by developing the "Third Age Suit". This toolkit is dedicated to designing cars with seniors in mind, ensuring that vehicles are not only functional and aesthetically pleasing but also considerate of the unique needs and experiences of older individuals (Pultarova, 2023) . The Third Age Suit replicates the physical and sensory changes associated with ageing, simulating age-related impairments such as reduced mobility, vision issues, and diminished dexterity.

GERT - Age Simulation Suit

From the opacity of the eye lens to the narrowing of the visual field, high-frequency hearing loss, head mobility restrictions, joint stiffness, loss of strength, reduced grip ability, and diminished coordination skills, GERT provides a comprehensive and immersive simulation of the physical and sensory challenges that often accompany ageing as shown in the image below (Timm, Spaderna, Rodermund, Lohr, Buettner, Berndt, 2020).

Image 1.3: GERT Age Suit

2.4 Sensory Simulations: SimSpecs

Image 1.5: Optima, Set of 6 Simulation Spectacles

Manufacturers like Connect offer simulation spectacles (sim specs) designed to replicate various conditions such as retinal degeneration, loss of vision, and reduced visual acuity, aiming to raise awareness of visual impairment (Connect Design, 2023). It is noteworthy that a fairly large range of manufacturers produce simulation spectacles, considering them among the most commonly utilised and readily available simulation tools, extending beyond design settings. They are even available on platforms such as Amazon rather than specialist retailers (See Image 1.6)

They have a specific focus on replicating a diverse range of symptoms of conditions that cause visual impairments. This is in contrast to the simulation glasses developed by the University of Cambridge, which provide a more general simulation of fading visual acuity through the use of foggy glasses. SimSpecs provides

simulations for a range of visual impairments, including hazy vision, left/right side vision loss, loss of binocular vision, retinal degeneration, reduction of visual acuity, tunnel vision, cataracts, horizontal diplopia, birdshot uveitis, and severe sight loss, restricting visibility to only light projections (Connect Design, 2023). Importantly, these simulations cover symptoms that can arise from a variety of different conditions. Additionally, other manufacturers offer simulation glasses specifically labelled with certain conditions rather than general symptoms. Among the commonly simulated conditions are Glaucoma, Cataracts, Macular Degeneration, Retinitis Pigmentosa, and Diabetic Retinopathy (see image below).

Image 1.6: Simulation Spectacles found on Amazon

Digital alternatives also exist, essentially functioning as filters. An illustration of this is the See Now Sight Simulator, utilising Google Maps to depict familiar locations through the lens of conditions

such as cataracts, glaucoma, and retinopathy (Clarke, K., 2017). The simulator allows users to adjust the severity of the displayed issues, showcasing the diverse diagnoses and experiences associated with vision loss. Additionally, the Sight Simulator provides on-screen information about the specific condition being viewed.

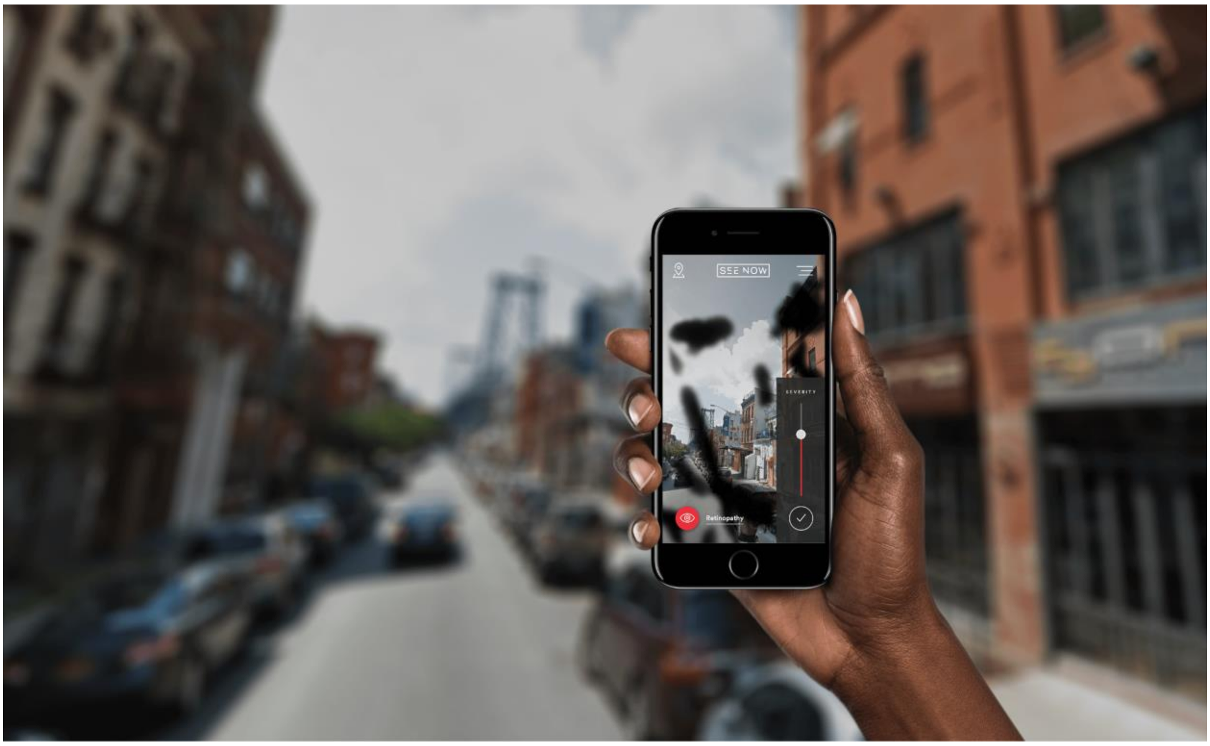

Image 1.7: See Now Sight Simulator

2.5 Neurodiversity simulations: The Harvard University Dyslexia Simulator

It is worth noting that simulations of neurodivergence and mental health conditions are less commonly used compared to the examples mentioned earlier. Typically, such simulations take the form of videos illustrating the experience visually. For instance, there are numerous videos simulating overstimulation to portray the autistic experience (National Autistic Society, 2017). An exception is The Harvard University dyslexia simulator, available on GitHub, which employs code created by Swedish web developer

Victor Widell (Harvard University, 2012). This tool alters text by keeping the first and last letters of each word constant while jumbling up the middle letters, replicating the visual experience of dyslexia. Originating from Widell's dyslexic friend, who described letters swapping in and out of place, the code can be applied to any web page to simulate the dyslexic reading experience.

Immersive Experiences

Many of these simulations focus on emulating the physical constraints, encompassing not only simulations of physical impairments like limited mobility but also those simulating sensory and psychological experiences. The exploration of emotional, psychological, and socially influenced factors is more likely to be found in the realm of immersive experiences. To illustrate, a few examples of immersive experiences are explored here.

2.6 Notes on Blindness- Into Darkness (VR experience)

The highly acclaimed narrative VR experience, "Notes on Blindness," takes participants on an emotional journey into a world devoid of sight, drawing inspiration from the real-life account of John Hull's experience with sight loss (Colinart, A., 2016). In 1983, after a gradual decline in vision over several decades, John Hull lost his sight completely (Colinart, A., 2016). Seeking to comprehend the profound changes in his life, he began documenting his journey on audio cassettes. These authentic diary recordings serve as the foundation for an interactive non-fiction narrative, providing a cognitive and emotional insight into the experience of blindness. The narrative unfolds through a distinctive combination of storytelling, art direction, and a graphical universe, enhanced by features like movement tracking,

spatialized sound, and interactive controls. The work is produced by Ex Nihilo and Arte France in collaboration with Archer's Mark, with Novelab Audiogaming as the executive producer (Colinart, A., 2016).

Image 1.8: Notes On Blindness- Into Darkness

2.7 Within Reasonable Accommodation

The installation "Within Reasonable Accommodation" by Stephen Lapthisophon, exhibited at Gallery 400, University of Illinois in 2002, challenged the public's response to accommodation policies for disabled individuals (Cachia, A., 2016). Lapthisophon strategically incorporated various elements such as ladders, sculptural intrusions, cardboard boxes, electrical cords, walkers, architectural details, images, signage, and obstacles to influence how visitors navigated the gallery space (Cachia, A., 2016). By reversing the typical access privileges, Lapthisophon empowered the disabled subject and placed the non-disabled figure in the minority, aiming to evoke empathy from the audience.

Image 1.9: Within Reasonable Accommodation, Gallery 400

This concept of reversing an environment, shifting from accessible to inaccessible for the mainstream, resonates with Finkelstein's short story depicting an "upside-down world"—a community organised and run by wheelchair users (Finkelstein, 1988). Disabled installation artists often explore this idea, making a powerful statement about their rights to accessibility and aligning with philosophies like the design model of disability.

2.8 Chaos

E&H LAB, a French creative agency specialising in corporate social responsibility, collaborated with MassiveMusic to create CHAOS, an immersive initiative exploring mental health complexities. Located at Saint-Lazare railway station within a brain-shaped dome, CHAOS portrays daily life navigation for individuals with mental illnesses through experiences involving shifts in darkness, electricity, and light, along with changes in speed, rhythm, and mood (Little Black Book, 2019). The integration of music and visuals enhances the immersive character, illustrating diverse

emotional states—from calmness to turmoil (Little Black Book, 2019).

Note

The examples in sections 2.9, 2.10 and 2.11 represent the author's personal endeavours in articulating both their own and others' lived experiences, mainly in the form of installations, experiments and education resources. Although not on the same scale as the previously mentioned examples, they offer conceptual and philosophical relevance. These instances experiment with a blend of simulation and immersive experience methods, aiming to contribute to the discourse surrounding disability narratives and design inclusion.

2.9 Daring Into Darkness

This exploration sought to convey the lived experience of blindness to a fully sighted audience using both an immersive experience (non-visual) and a graphic narrative (visual). Drawing inspiration from Merabet and Alvaero Pascual-Leone's studies (Pascual-Leone, Amedi, Fregni, Merabet, 2005; Merabet, Swisher, McMains, Halko, Amedi, Pascual-Leone, Somers, 2007; Pascual-Leone, Obretenova, Merabet, 2011) which revealed cognitive changes after five consecutive days of sensory deprivation, the artist, already familiar with visual impairment, conducted an eight-day experiment of complete sight deprivation through blindfolds. The insights from this experiment informed the creation of the installation "Whispering Walls" and the immersive exhibition "Daring Into Darkness", both expanding on the findings of the initial study.

"Daring Into Darkness" aimed to challenge the stigmatised perception of blindness, prompting a conversation about how

visually impaired individuals perceive the world and what we can learn from their perspective. This effort was motivated by a desire to shift away from deficit-based narratives surrounding visual impairment and instead educate people about alternative ways of seeing and navigating life. The exhibition was showcased as part of the Royal College of Art Degree Show in 2017.

2.10 Colour Embodied

Colour Embodied, a Friday Late event at the National Gallery during the Monochrome season, creatively explored alternative colour perception experiences. Comprising a talk, workshop, and pop-up exhibition, the initiative focused on non-visual and embodied aspects of colour perception as a culturally learned behaviour tied to pattern recognition. The talk provided scientifically grounded insights into colour perception, particularly within visually impaired individuals, while an interactive workshop allowed participants to test their pattern recognition in relation to colour perception. Blindfolded visitors categorised objects on a table based on tactile inputs and other sensory cues, demonstrating the brain's role in vision. This event aimed to shift away from deficit-based perceptions of individuals with visual impairments by showing how much of visual processing really happens in your brain as opposed to your eyes.

2.11 How We See

This 18-month design research project, conducted in collaboration with the Royal National Institute of Blind People (RNIB) and the Helen Hamlyn Centre of Design at the Royal College of Art, aimed to break the stigma and reshape the representation of individuals with invisible disabilities. Inspired by the RNIB's viral video #How

I See, the project, titled How We See, resulted in various resources for both internal and external use by the RNIB:

RNIB Volunteer Pack on 'How We See':

- **Materials for visually impaired volunteers to conduct school sessions on sight loss. Addresses misconceptions about blindness, confusing language, and stereotypes.**

'How We Sense' Resource:

- **Designed for teachers to integrate relevant topics on sensory diversity and sight loss into various subjects (Science, English, Maths, and PSHE). Includes lesson plans aligned with the school syllabus and uses immersive experience activities to maximise student engagement.**

RNIB Briefing on Disability Narrative:

- **Informed by project findings, this resource offers guidelines for a contemporary, human-centred disability narrative. A shift from traditional, deficit-based communication to more timely and inclusive approaches.**

While the simulations and simulation toolkits explored in this section seem to hold significant promise for designers to craft products and environments that consider a diverse range of user experiences (Cardolo, C. and Clarkson, J., 2010), the paradox emerges: even with the best intentions, the intersection of empathy and exclusion through simulations can leave a shadow (Flower, Burns, Bottsford-Miller, 2007).

3. An Illusion of Inclusion - How Things Go Wrong

This section aims to scrutinise the challenges and potential pitfalls associated with the utilisation of simulation toolkits in design. It will explore scenarios where well-intentioned efforts to promote empathy, paradoxically result in a form of exclusion that may not be immediately apparent (Silverman, 2015; Wright 1978), leading to what could be termed an "illusion of inclusion". Understanding mentalities around inclusion, user experience and disability becomes paramount in unravelling and understanding the complexities that may underlie the pitfalls of simulation toolkits.

3.1 Understanding (Psychosocial) Inclusion: Beyond Physical Barriers

In the realm of design, the pursuit of inclusion has traditionally centred on the removal of physical barriers, with a primary focus on tangible, concrete accessibility measures (Kille-Speckter, Nickpour, 2022). While addressing these barriers is undoubtedly a crucial facet of the inclusive design process, it is equally important to recognize that genuine inclusion extends far beyond the realm of physical impediments. Simulation toolkits, while invaluable for fostering awareness of physical limitations, can inadvertently perpetuate the "illusion of inclusion" when they fail to address the intricate psychosocial dimensions of design exclusion. To fully appreciate the holistic experience of users, designers must extend their understanding beyond the physical dimensions of inclusion.

Psychosocial inclusion is characterised by the psychological, sociological, cultural and value-related barriers that contribute to design exclusion (Nickpour and Jordan 2012; Lim and Nickpour, 2016; Lim, Giacomin, and Nickpour, 2020). Psychosocial inclusion plays a pivotal role in determining the success of any inclusive design endeavour. It underscores the reality that for many individuals facing exclusion, the social and psychological factors can often present more significant barriers than the physical obstacles (Nickpour and Jordan 2012; Lim, Giacomin, and Nickpour, 2020; Shakespeare, 2013). Unfortunately, these psychosocial factors are frequently underrepresented or entirely overlooked in the development and application of simulation toolkits. In the pursuit of empathetic design, it is essential to recognize that the experience of exclusion or inclusion is not solely determined by the absence or presence of physical barriers. Rather, it is a multifaceted interplay of emotional well-being, social connectedness, psychological comfort, and cultural relevance. It is this complex interweaving of psychosocial factors that often dictates the level of inclusivity achieved by a design (Nickpour and Jordan 2012; Lim and Nickpour, 2016; Lim, Giacomin, and Nickpour, 2020).

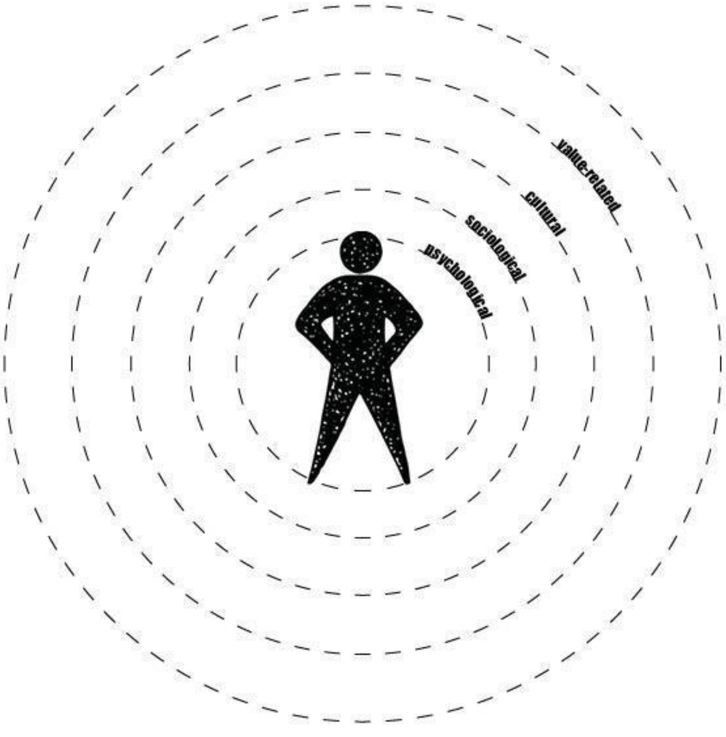

Image 2.1: Layers of psychosocial inclusion

To foster inclusivity, a solid understanding of essential user experience principles is indispensable. A thorough exploration of user experience and the foundations of good design is imperative for achieving psychosocial inclusion in design. Conventional adaptations, like non-integrated ramps and other accessibility go-to's, prompt inquiries into their impact on social interactions and the risk of creating divisions among users.

3.2 Understanding User Experience: Beyond Accessibility and Functionality

Regardless of whether our design targets the mainstream or a niche audience, the foundation of good design can be further explored in consideration of the hierarchy of design needs (as shown below in the UX Hierarchy of Needs) which draws inspiration from Maslow's hierarchy of needs (Anderson, S. P., 2011). By adhering to the layers of functionality, reliability, usability, convenience/ proficiency, pleasure, and meaning, we ensure that our designs not only meet their intended purpose but also resonate with users on a profound and meaningful level. This approach transcends the mere aesthetic or functional aspects, emphasising a comprehensive understanding of the diverse layers that contribute to a successful and inclusive design experience. This evolved hierarchy underscores that successful design necessitates addressing each layer comprehensively (Anderson, S. P., 2011), reinforcing the argument for psychosocial inclusion by acknowledging the multifaceted aspects of user experience beyond mere physical functionality.

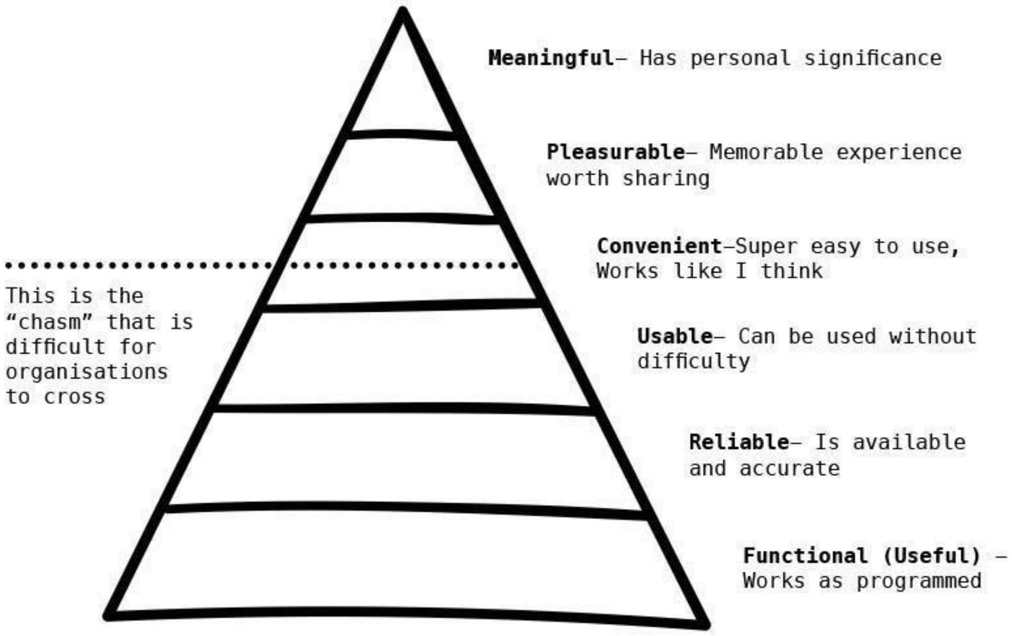

Image 2.2: UX Hierarchy of Needs

Continuing with this line of thinking, the principles outlined in the book "Emotional Design" by Don Norman further reinforce the connection between the hierarchy of design needs and psychosocial inclusion. Norman explores the concept of three distinct levels of experience, each corresponding to different levels of design. The first level, Visceral Design, operates on a subconscious, immediate reaction to sensory stimuli (Norman, D. A., & Ortony, A.,2003). For instance, encountering a landfill elicits an instinctive negative response, while the anticipation of a luxury car exhibition evokes positive, anticipatory feelings (Norman, D. A., & Ortony, A.,2003). The second level, Behavioral Design, correlates with the usability and convenience layer, delving into the practical and meaningful aspects of user experience during product use—focusing on how it feels, looks, etc (Norman, D. A., & Ortony, A.,2003). Norman's concept underscores that achieving meaningful design necessitates passing through the visceral design test, mirroring the layered approach of the design

hierarchy. The third level, Reflective Design, aligns with the pleasure and meaning layers, emphasising experiences beyond initial use, such as associations, familiarity, and retrospection, that influence long-term perceptions (Norman, D. A., & Ortony, A.,2003). This nuanced dimension echoes the psychosocial inclusion argument, highlighting the significance of understanding the overall user experience, including emotional, social, and cultural aspects, to create designs that resonate inclusively with users.

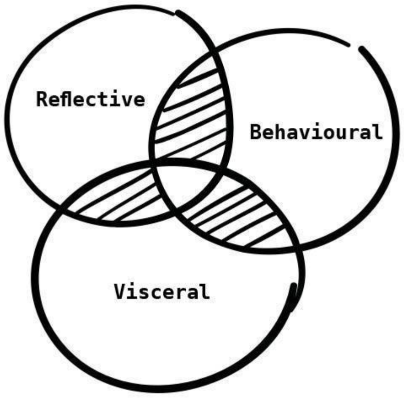

Image 2.3: Donald Norman's Three Levels of Design

As we unravel the multifaceted layers of design inclusion and user experience, it becomes evident that the pursuit of inclusivity demands a comprehensive understanding beyond the tangible. This sets the stage for our exploration of (disability) narratives, which wield significant influence on shaping perceptions and, ultimately, impacting lives (Shakespeare, 2013).

3.3 The Power of Narrative: Shaping Disability Narratives and Impacting Lives

Narratives, as conduits of human experience, are powerful tools that shape our understanding of the world (Bruner,1991). They

influence the way we perceive others, construct our identities, and navigate the complex terrain of disability. In the realm of design and empathy, narratives play a crucial role in both reflecting and moulding our attitudes toward disability (O’Sullivan and Nickpour, 2022).

There is no singular narrative of disability, but rather a rich tapestry of diverse stories, each offering a unique perspective on what it means to live with a disability. These narratives are not just stories but also integrations of experiences, beliefs, and societal constructs. They wield the power to elevate or disempower, to inspire or marginalise (Kille-Speckter and Nickpour, 2022). To truly understand and appreciate the multifaceted nature of disability, we must examine the narratives that surround it. Therefore, narrative analysis holds considerable promise in the field of design, fostering a deeply humanised design process by cultivating empathy, enriching multi-sensory conceptualisation and visualisation, and facilitating holistic designing (Danko, 2006, p.1).

Within the sphere of disability narratives, two predominant models emerge: the Medical Model of Disability and the Social Model of Disability. These models provide distinct frameworks through which society comprehends disability and subsequently informs the design process. It is critical to recognize the impact these models have on individuals' lives and their experiences. In addition to these widely recognised models, we will also delve into lesser-known but equally impactful models of disability such as the Design Model of Disability, and an extensive chronological list of existing models of disability for reference, offering a comprehensive understanding of the evolving narratives surrounding disability.

3.3.1 The Medical Model of Disability

The Medical Model of Disability traditionally views disability as a personal deficit, an inherent flaw within the individual. It places the focus on the individual's impairments and shortcomings, often framing them as medical issues to be treated or fixed (Guffey and Williamson, 2020). This model tends to pathologize disability, emphasising medical diagnoses and interventions to bring individuals in line with the "norm" (Guffey and Williamson, 2020).

This enthusiasm for disabilities being fixed - particularly through advanced technology - is still reflected nowadays in phenomena such as techno-ableism (Kille-Speckter and Nickpour, 2022). Simulations, by replicating physical limitations, may inadvertently reinforce this deficit-oriented perspective, mirroring the approach of pathologising disability and seeking solutions that compare individuals with a perceived "norm." Consequently, examining the alignment between simulations and the Medical Model of Disability highlights the potential implications of simulation tools in perpetuating a deficit-focused narrative around disability.

3.3.2 The Social Model of Disability

In contrast, the Social Model of Disability shifts the narrative from individual deficits to societal barriers (Shakespeare, 2013). It posits that disability is not solely an intrinsic condition but is exacerbated by societal structures, attitudes, and physical environments that do not accommodate diverse needs. This model emphasises that disability is as much a result of environmental and societal factors as it is of individual impairments. It is a narrative that focuses on empowering individuals by removing societal barriers to their participation and inclusion.

3.3.3 The Design Model of Disability

The emerging design model of disability challenges traditional perspectives by asserting that disability is a result of design shortcomings within a given space leading to individuals being disabled by design (Guffey and Williamson, 2022; Hendren, S., 2020; Kille-Speckter and Nickpour, 2022).

The design model of disability introduces a paradigm shift by emphasising the critical role of designed spaces in shaping the experiences of individuals with disabilities (Hendren, S., 2020). In this model, disability is not an inherent trait of an individual, nor is it solely a consequence of societal attitudes or structures. Instead, disability is viewed as a product of the interaction between an individual and the designed environment (Hendren, S., 2020). This perspective underscores the significance of creating inclusive and accessible designs that cater to a diverse range of abilities.

The design model encourages a proactive approach, urging designers to anticipate potential challenges and eliminate barriers before they become impediments.

3.3.4 An overview of Models of Disability

In addition to the narratives presented through the outlined models of disability above, a chronological list of disability models, along with their commonly understood narratives, is provided below (Kille-Speckter and Nickpour, 2022).

Disability Model	Language keywords	Details
The Religious Model of Disability	*Sin, shame, act of god, divine punishment*	Oldest model of disability, punishment by God(s)

The Moral Model of Disability	*Sim, moral, spiritual, belief*	Morally responsible for their own disability (mid 1800)
The Eugenic Model of Disability	*normal/abnormal, fit/unfit, undeserving, inferior*	Theory of eugenics, being fit or unfit physically
The Biomedical Model of Disability	*Biology, impairment*	Dominant in the western World, focus on biological factors only
The Biopsychosocial Model of Disability	*Undeserving, unwilling, lazy*	Developed by private health insurance in US and UK, responsibility on disabled person
The Medical Model of Disability	*Cure, treatment, disease, care*	Disease or trauma to be cured
The Professional Model of Disability	*Impairment, limitation, improvement, treatment, patient*	Related to medical model, perspective of experts
The Charity Model of Disability	*Tragedy, itty, shame, victim*	Disabled people as victims of circumstance
The Economic Model of Disability	*Socio-economic, impairment, assessment, productivity, (un)employment*	Personas inability to work/ being a productive member of society
The Identity Model of Disability	*Minority, disability as identity, membership*	Disability as a positive identity
The Social Model of Disability	*Social construct, phenomenon, integration, rehabilitation*	Phenomenon which is socially created
The Affirmation Model of Disability	*Normalisation, deinstitutionalization, disability pride, social*	Critique of the charity/tragedy model, disability as an everyday occurrence which is neither negative nor positive

	identity, impairment, arts, non-tragic, diversity	
The Minority Model of Disability	*Experience, normalisation, social barriers, imposed, impaired*	Sociopolitical,social barriers and negative attitudes imposed on individuals
The Market Model of Disability	*Identity minority, economic, user, market, empower*	Minority rights and consumerist model, disabled people as stakeholders and consumers
The New Radical Model of Disability	*Disabled person, rights, disability justice,intersectionality, social justice, crip, mad (reclaimed)*	Does Not distinguish between impairment and disability
The Spectrum Model of Disability	*Mankind, function, reduction, operation, disability*	Disability on a sensory spectrum of humankind
The Relational Model of Disability	*Built environment, normalisation, diversity, support, deinstitutionalization*	Normalising access and social inclusion
The Socially Adopted Model of Disability	*Ableism, environment, limitations, society*	Limitations of able-bodied society, social barriers
The Empowering Model of Disability	*Empower, individual, choice, treatment*	Professionals as service providers
The Legitimacy Model of Disability	*Value-based,membership, collaboration*	Disability as a value based determination
The Human Rights Model of Disability	*Human rights, social justice,independence, voices, discourse,*	Human rights based and anti-discrimination (1980s)

	discrimination

Many of the existing narratives surrounding disability can be characterised as ableist, stigmatising, reductive, and in themselves disabling (Shakespeare, 2013). It is therefore vital to appreciate the implications of these narratives on individuals' lives and experiences (Silverman, Gwinn, Van Boven, 2015). To break down these narratives and cultivate empathy, designers must be attuned to the general consensus of disability narratives and work to challenge and redefine them.

3.4 Lived-Experience Insights: Exploring Simulations of Disability

The journey toward genuine empathy in design is a multifaceted endeavour, and one of the most enlightening perspectives can be found in the lived experiences of individuals who face the unique challenges of disability on a daily basis (Silverman,2025).

In this subsection, we embark on an autoethnographic exploration of the short and long term impact that simulations and empathy toolkits have had on the author, who has lived-experience of a visual impairment. It sheds light on the nuances and intricacies of experiencing one's own disability through the lens of a simulation. This lived-experience narrative serves as a testament to the multifaceted nature of empathy in design, a reminder that achieving true empathy requires an appreciation of the personal, emotional, and psychological dimensions.

The narrative will now transition to a first-person perspective, allowing for a descriptive and reflective exploration of key aspects of the author's experience.

“My journey with simulations began at the age of 16 when I was diagnosed with Stargardt's disease. The condition predominantly affects my central vision, resulting in blind spots within my field of vision, which has significant implications for colour perception and detail recognition.

My very first encounter with simulations occurred while I was still in school. A charity supporting individuals with sight loss organised a ‘day of empathy’ to explain my condition to my fellow students. They handed out simulation glasses specifically designed to replicate the experience of Stargardt's disease, and tasked the students with performing various activities while wearing these glasses. It was an attempt to provide them with insight into my daily challenges.

From the perspective of the students who participated, the simulation glasses were received like a game; something fun to play with. There was an element of curiosity and novelty as they navigated their surroundings with altered vision. However, it also unintentionally turned into an exercise of pity, as they struggled to cope with the limitations imposed by the simulation glasses.

I myself wanted to try the simulation glasses and was shocked how unrealistic the simulation was. As previously mentioned, I have blind spots in my central vision, however they are not actually visible for me as my brain in a sense, fills in the blanks like a live streaming optical illusion. Nor do I experience any notably visible effect of my sight loss such as blurriness. However, the simulation glasses are very literal in their interpretation of certain effects such as black splotches on the glasses representing the blind spots. The activities the students were asked to perform and struggled with, were also not things I struggled with, perhaps because you quickly adapt when you actually live with a specific

condition. It certainly did not feel like it was accurately representing my experience, my difficulties, or my needs.

I was absolutely devastated after this experience, as my peers confirmed that having my disability was something to pity me for. Essentially making me feel less than. This, if anything, made me feel more excluded as it highlighted the rift between mine and their experience. There was no element of empowerment, empathy, or even real understanding but rather I felt hopeless and weighted down by the stigma I was now facing. This encounter in response shaped my coping strategies and marked the beginning of my understanding of the social implications of being labelled as disabled. For many years after, I felt uncomfortable disclosing my disability to others, instead hiding it fairly effectively, because I did not want to experience the inevitability of being reduced to my disability. Because I have an invisible disability, I could camouflage but this also meant I would not ask for the help I needed but stubbornly pressed on without tools that could have been helpful. It did not help that a lot of tools designed for accessibility do not fulfil the criteria outlined previously in the UX hierarchy of needs. These objects of disability (Guffey and Williamson, 2022) made me feel like I was drawing attention to my limitations, highlighting my differences, and inviting others to stigmatise and pity me.

Being a researcher and practitioner in the field of inclusive design, I have since come across many forms of simulations of disability and have observed a similar pattern when it comes to how it shapes people's perception of disability and continues a deficit-based narrative. I have since used my frustrations with this initial experience of simulations to explore ways to communicate my and others’ lived- experience in a way that is not focussed on physical limitations alone.”

3.5 A closer look at Simulations of Disability: Critical Analysis

This experience with SimSpecs mirrors many of the challenges that can arise when simulations are used, either in an educational context or within the design industry. This example demonstrates how simulations can, in some cases, create a divide between those simulating a disability and those who genuinely experience it (Silverman, Gwinn, Van Boven, 2015) and serves as a reminder that the use of simulations should be approached with care and consideration.

Thankfully, when designers use these tools, it is often not in the presence of individuals affected by the simulated conditions. However, the impact on the able-bodied designers remains the same. The potential for simulations to perpetuate exclusion and ableism, even unintentionally, underscores the need for a critical examination of their role in the design process.

Simulations of sight loss, such as the one detailed earlier, are also frequently employed beyond the design context. They serve educational purposes, enlightening school children about disabilities, and providing training for professionals working with the disabled (Flower, Burns, Bottsford-Miller, 2007). Consequently, it is crucial to note that the described experience is not unique to the author; its potential pitfalls have long been recognised and actively critiqued by disability activists (French, 1992; Maurer, 2012; Willoughby & Duffy, 1989). Furthermore, experimental psychologists have recently brought attention to these concerns as well (Silverman, 2015). However, not many critical perspectives on simulations and simulation toolkits have been documented in papers from within design.

While studies suggest that simulations can enhance empathy by tapping into how individuals anticipate their own reactions in similar situations (Clore & Jeffery, 1972; Van Boven, Loewenstein, Dunning, & Nordgren, 2013), it's essential to recognize potential drawbacks, particularly for the group being "represented." Many challenges faced by people with disabilities stem from social interactions laden with narratives of pity and paternalism (Ferguson, 2001; Fiske, Cuddy, Glick, & Xu, 2002; Nario-Redmond, 2010; Omvig, 2002; Wright, 1983). Placing excessive emphasis on physical factors tends to divert attention from the substantial impact of social barriers and discrimination, which often only become apparent gradually over time (French, 1992).

Disability simulations often adopt an "outsider-driven" approach, appealing to non-disabled individuals seeking a glimpse into the disability experience. However, disability activists, often considered "insiders," raise concerns that these simulations may portray their experience in a biased manner and are not an accurate representation of their lived-experience (Silverman, 2015).

Contrary to the belief that participants in disability simulations are gaining insights into the reality of disability, the experience often mirrors the initial encounter with a disability, not the prolonged experience of living with one. While the onset of a disability can indeed be traumatic, individuals tend to adapt over time, employing alternative techniques, building support networks, and focusing on unaffected aspects of their lives (Ubel, Loewenstein, & Jepson, 2005).

Participants in disability simulations frequently report feelings of frustration and distress, even if they overall rate the activity positively. For instance, after a blindness simulation, participants

expressed loneliness, fear, and helplessness as "new insights gained into the life of the disabled" (Wilson & Alcorn, 1969, p. 305-6). In contrast, individuals with long-term disabilities consistently report high levels of happiness and quality of life (e.g., Albrecht & Devlieger, 1999; Bonanno, Kennedy, Galatzer-Levy, Lude, & Elfstom, 2012; Quale & Schanke, 2010). Therefore, the negative sentiments often experienced in simulations diverge significantly from the actual emotions reported by individuals with disabilities.

"*Simulations cannot capture the nuances and long-term effects. Consequently, simulations can give the mistaken impression that the entirety of being disabled is marked by loss, frustration, and incompetence*" (Silverman, 2015)

Due to this concern, scholars in the field of disability studies have warned that simulations may inadvertently give participants a misleading impression of the realities of living with a disability. According to Wright (1978) "t*he main danger of role-playing is that the essence of life of people with a disability will be perceived in negative terms*" (p. 182).

In summary, this section extensively examines the intricacies of inclusion, extending the discussion beyond physical barriers and functionality. Through a thorough exploration of disability narratives, including a detailed analysis of lived experience with disability simulations, the complexities and potential shortcomings in the pursuit of authentic inclusion come to light. Navigating through these challenges, the following section will delve into strategies and considerations for fostering a more inclusive and balanced approach in the realm of design for inclusion.

4. The way forward; acknowledging the tensions and navigating the polarities

In light of the identified pitfalls in simulation toolkits discussed earlier, this section aims to explore mentality shifts, points for discussion and proactive measures for designers. The focus is on overcoming challenges within our design practice and devising innovative strategies going forward.

4.1 Simulation vs Immersion

In a preceding section, we explored the landscape of simulation toolkits and immersive experiences, underscoring the diverse approaches to representing lived experiences. The stark contrast between simulations and immersive experiences lies in their purpose and nature (Cardolo, C. and Clarkson, J., 2010); the former is designed to be measurable, replicable, and function-focused, while the latter is abstract, interpretation-based, and intended to provoke thought rather than serve a functional role in a user testing scenario.

While the contextual divergence between these two branches is understandable, there is potential for cross-pollination of ideas. Simulations aim to foster empathy and yield actionable insights (Cardolo, C. and Clarkson, J., 2010), yet simplifying lived experience within current measurable formats, as discussed earlier, comes with inherent drawbacks (Silverman, 2015). It prompts the question of whether simulations could benefit from departing from singular, measurable formats and instead embrace the complexity inherent in psychosocial dimensions, narratives, and a more diverse range of experiences. Examining potential lessons from immersive experiences that could enhance

simulation toolkits for increased effectiveness in fostering inclusion and understanding of lived experience. Here are several key aspects that simulations could consider adopting:

1. ***Complexity and Nuance:*** **Embracing the multifaceted dimensions of psychosocial factors - the interplay of emotional, social, psychological, and cultural factors (Nickpour and Jordan 2012; Lim and Nickpour, 2016; Lim, Giacomin, and Nickpour, 2020), diverse narratives, and a range of experiences that reflect the intricacies that individuals with disabilities navigate daily, could enhance the authenticity of simulations.**
2. ***Storytelling and Narrative Frameworks:*** **Storytelling and narrative frameworks can engage audiences emotionally and intellectually. Incorporating these elements into simulations could create a more immersive and empathetic learning environment that fosters a deeper connection to the subject (as seen in the example of *Notes on Blindness*, see 2.6).**
3. ***Diverse Representation:*** **Simulations benefit from broader representation of disabilities and lived experiences, ensuring a more accurate portrayal of the disability spectrum and avoiding pitfalls of oversimplification that leads to the perpetuation of stigmas stereotypes (Ferguson, 2001; Fiske, Cuddy, Glick, & Xu, 2002; Nario-Redmond, 2010; Omvig, 2002; Wright, 1983).**

By embracing complexity, leveraging storytelling, and ensuring more diverse representation, simulations have the potential to elevate their effectiveness and offer a more nuanced and inclusive perspective on disability.

4.2 Psychosocial simulations?

Exploring the development of simulations that encompass psychosocial dimensions presents a challenging yet promising avenue. While the inclusion of psychosocial dimensions undoubtedly increases the complexity of the simulation, it aligns with the evolving understanding of disability and the multifaceted nature of user experiences (Nickpour and Jordan 2012; Lim and Nickpour, 2016; Lim, Giacomin, and Nickpour, 2020). Considerations could be given to whether simulations could be designed to explore psychosocial dimensions individually, allowing for a nuanced examination of factors such as social interactions, emotional well-being, and cultural relevance.

Moreover, existing platforms like *The Exclusion Calculator* by the University of Cambridge (see 2.2) could explore the integration of factors related to psychosocial inclusion. This may involve highlighting potential psychosocial implications of introducing questions that prompt users to consider the broader dimensions of disability experiences. Embracing psychosocial dimensions within simulations not only aligns with a more comprehensive understanding of disability, but also opens up opportunities for richer, more empathetic design insights that go beyond the limitations of purely physical simulations.

4.3 Learning from other disciplines

For the purpose of problem solving (Cardolo, C. and Clarkson, J., 2010), designers often gravitate towards functionality, leveraging simulations to efficiently address specific challenges within constrained timeframes. This tendency is further accentuated by adherence to established requirements that may take precedence over creative experimentation.

However, this adherence to known methods and standards can lead to a certain level of stagnation, limiting the potential for true innovation and the discovery of alternative approaches.

Lessons from other disciplines:

1. Inclusive performance arts actively embrace exploration and experimentation, pushing the boundaries of traditional practices. Embracing a mindset that values exploration over rigid adherence to established norms could potentially offer a pathway to the evolution of simulation methodologies or even the emergence of viable alternatives.
2. Critical disability studies often advocate for a shift from deficit-based perspectives to capability-based thinking reflecting approaches found in the social and design model of disability. Designers can learn to focus on the strengths and capabilities of users, celebrating diversity and leveraging it as a source of innovation rather than viewing it as a set of limitations.
3. Similarly, social science emphasises the importance of understanding intersectionality - the interconnected nature of social categorisations. Designers can learn to consider the intersectionality of user identities, recognizing that individuals possess multiple dimensions that influence their experiences and needs.

All three disciplines underscore the importance of greater holistic understanding and exploration of inclusion. By drawing inspiration from these disciplines, the field of design has the potential to evolve beyond conventional practices, fostering a more inclusive, empathetic, and innovative design landscape.

4.4 Lived Experience

Continuing this exploration, it becomes evident that educational activities addressing disability should not merely simulate or replicate experiences but actively integrate the lived experiences of individuals (Silverman, 2015). This approach, as highlighted, involves projects grounded in the recorded experiences of disabled people or direct engagement with those who have first-hand knowledge. Instead of fixating on limitations, the focus should shift towards a more enlightening exploration of how differences shape interactions, workarounds, and preferences. This approach not only provides a richer learning experience but also contributes to a more comprehensive understanding of the diverse aspects of lived experience such as disability.

Furthermore, the inclusion of more lived-experience designers and researchers is not just beneficial but pivotal for fostering a truly inclusive design landscape. Drawing from the unique insights and perspectives of individuals with lived experiences of disability adds authenticity and depth to the design process and ensures that the resulting designs are more attuned to the real needs and nuances of individuals. Embracing lived-experience designers and researchers reflects a commitment to genuine inclusion and positions them as integral contributors to the evolution of inclusive design practices.

5. Conclusion: Empathy in Design - A Call to Do Better

In exploring simulation toolkits, the complexities and nuances of inclusion become evident. These tools have the potential to foster understanding but also create a complex paradox, resulting in an "illusion of inclusion". As we conclude, reflection on lessons to be learned prompts consideration of improvement.

So, how can we do better?

1. ***Expand Understanding of Inclusion:*** **It is essential to broaden the narrative of empathy in design to encompass psychosocial dimensions, considering psychological, sociological, cultural and value related factors (Nickpour and Jordan 2012; Lim and Nickpour, 2016; Lim, Giacomin, and Nickpour, 2020).**
2. ***Challenge Ableist Narratives:*** **Actively challenging and redefining ableist narratives of disability, shifting the focus from individual deficits to societal barriers and in some cases design shortcomings (Guffey and Williamson, 2022; Hendren, S., 2020; Kille-Speckter, Nickpour, 2022, Shakespeare, 2013).**
3. ***Critical Application of Simulations*****: Simulations and simulation toolkits should be used thoughtfully and critically. Designers should be aware of the potential pitfalls and complexities they may introduce (Silvermann,2015). It is crucial to avoid the "illusion of inclusion" and strive for a genuine understanding of diverse experiences.**
4. ***Embrace Lived-Experience:*** **Lived-experience insights offer a unique vantage point. These insights should be embraced to guide the development and application of simulations and empathy toolkits, ensuring their effectiveness and relevance (Silvermann,2015).**
5. ***Continual Learning*****: Inclusion in design is an ongoing journey. Designers, educators, and individuals alike must continually learn, adapt, and evolve their understanding of empathy, inclusivity and disability, for example by looking at insights from other disciplines.**

In conclusion, the pursuit of empathy in design is a multifaceted endeavour that demands attention to psychosocial dimensions,

the reshaping of narratives, critical application of simulations, a commitment to embracing lived experiences and expanding the boundaries of our existing practice. By doing better, we can bridge the gap between the "illusion of inclusion" and genuine inclusion, fostering a more empathetic and inclusive design landscape for all.

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Letter from the Chairman's Desk

By Sunil Bhatia PhD

Wishing our esteemed readers and contributors A prosperous Happy New Year 2024.

Prof Choi is an established name and highly regarded designer, and academician in the design community, once wrote a statement
"In the same way that good design is not enough, human-centered design is not enough either. While 'human-centered' is about humans, 'humanity-centered' is about how we respect all - humans and non-humans, on Earth and elsewhere. Design is the last hope for humanity".

In modern context it is valid but if you go back in the past this statement has no relevance. Ancient people were not skilled designers but aware that the designed products for making their life better were never human-oriented. It was designed as humans as one of the users and primarily human oriented. They never missed the concept that a designed product should silently guide and make it learn how to achieve its goal for it is designed. This was the beauty in their designed products but we lost their philosophy somewhere in industrialization for making commercially viable products suits for mass production. Mass

production demands lots of compromises that suit the machine limitations and support the high volume of productions.

I am personally admirer of the folk wisdom of the primitive people who designed the products that silently guide the users to achieving their designed goal. There is an ancient butterfly yo-yo toy that has two wheels attached to the axle, one end of the thread is attached to the axle and the other end is in the hand of the player. It is the toy that keeps guiding the user to achieve a specific pattern of functioning of the thread for enjoying the movement of the wheel. It will not function for it is designed unless and until follow what product is guiding.

Sometimes designed products have many functional applications for users and it reason of conflict for users. Our designers started working on resolving that conflict and ultimately a product surfaced that is meant for what the user is supposed to use. When we restrict the function of the products or controlling conflicts of the surfacing of various function of the product by users give birth to hostile design. Ancient people design a product that has no element of hostile design. My philosophy is that the designer should design the products/ services to that level where the functional conflict for operation should not surface partially or completely and it should have an inner mechanism to guide the users for what purpose it is designed.

There is a popular phrase in the literature that has a message for designers 'The question is not who ignited fire for the burning village but who gave the match stick?' These result phrases come into life after a long period of observations. It is the match stick that guides the insane or mentally imbalanced person to ignite a fire with the match stick. Another example of a monkey that

somehow acquired a manmade razor of shaving and people around are scared not to hurt by his holding razor. Here whoever is holding is not important, rather the razor will keep doing what it is designed for. The monkey is not harmed by holding a razor . The design of the razor prevents users from harm by holding a sharp edge . It will not harm the user as it holds the handle but others will be harmed by sharp edges .Who holds the handle of the razor is declared as the user and how it will be used is the wish of the users.

Design of a tricycle or walker for learning walkers for toddlers is designed in such a way that the user holding the bar pushing is natural because the child's body weight on it helps in walking. As the child grows and pedals the two-wheelers and chances of falling due to not learning the art of balancing the designer has provided two side-wheeled stands that balance as a user in an imbalance state and fall is averted.

Mother is the best example when she teaches the child to utter some word. She keeps repeating till he learns by listening and imitating the same by following the resonances of her voice. I was shocked to see the newly born baby elephant allowed to stand and walk on his feet after a few minutes of birth . It is the child itself learns from the design of body structure that guides on stand on his feet.

One day my father was having dinner and I cooked his favourite dish. His comment was "How did you manage that seasonal vegetable?" I said it is old fashioned at present times that all the vegetables of any season are available. His concluding remark was “It is not as tasty as what we enjoy in real season". This statement made me think in order of user and product. It is the

season that makes every flower bloom and it is not that all the flowers of specific will bloom makes that season character. It is the specific season that makes every flower grow that needs proper growth. An artificial environment for the flower can bloom but elements of a certain specific character that makes its unique features will be absent or lower in the final result. Nature has its way of guiding the seeds by providing the type of bacteria that is required for the proper growth of the plants for bearing fruits. It is something like a bodybuilder shaping his body with artificial means by taking protein-rich diets and exercises. Can they run for miles and miles as our hunter does for hunting animal foods?

Ancient designers believed humans were the ultimate users and treated them as stationary and dumb and nothing could be expected from them and designed the products keeping in mind the changing environments. Man was living on trees and occasionally comes to earth in search for satisfying his physiological needs. As he needs were satisfied he again climbed the tree for safe living. It took man to centuries to live on earth leaving the tree. This philosophy of urge for adopting new environment has message that people wish to be part of continuation of civilization and same time to progress.

Modern designers expect the minimum common sense of the users. This promises to lead to interaction. Where ancient time's interaction with the product may be animal or human makes no difference. Here my intention is not to write about the obstacles they may face in the specific environment, rather it is a hurdle or obstacles that might arise with the changing environment. They work with this philosophy and design products that prove everlasting and highly improvised over the years where the scope of changing design is least. Painting is an ancient practice and it

was threatened with the technology of photography. Painters were complaining 'How come photography will be an art?' As technology further improved digital art surfaced and photographers made the same complaint. 'Digital art can in no way be an art in any sense.' They prove wrong. Currently, digital arts are under threat from Artificial Intelligence. The basic concept of painting was retention and was not bothered for means. The journey from rock painting to the use of artificial intelligence is retaining what painting has evolved with the objective but the means are different.

I was enjoying my dinner sitting on the dinner table when suddenly a bowl of cooked vegetables fell. My floor was spoil and immediately came in mind there is no point to again put it in bowl for eating but I refused to do so because my mind was trained it is affected food no more good for my health. I thought let me first finish my dinner with safe food then I will go for cleaning the floor. I was about to clean the floor. I noticed small microscopic living beings were visible with naked eyes on spilled food on the floor. I realized the most important part of any living being is smell. Human sperm attack the female as it smells the hormones released within the ovary. Even humans are crushed to death but the last thing left in the body is smell. Similarly other living beings use all the time of smell for their survival. Tragedy with the modern designer they have not yet exploited this smell organ to the optimum for making their products better for users. I realized adding the spices were an attempt to keep the foreign element for the food by suppressing its natural fragrance to avoid attraction.

I found the vegetables are food for others but the presence of it may harm the health of the person. Humans' all effort to keep avoiding the foreign element may cause harm to the body not allow such sharing at any possible time. He designed cooked food

to kill those foreign elements that were present in food by frying, boiling and roasting. He wished for even cook for proper killing. They designed an iron bar inserted into raw food pieces for even roasting by rotating over flame. Real taste comes with proper presence of carbon in the outer surface of the cooked food .He further designed a barrier for such harmful elements by boiling and frying by stirring and ups and down with a ladle for even cooking .

The design of ladle is such that it keeps users guided by its design and how to use it for its designed objective. A metal handle bar has one end for the user for holding and the other has a bowl shape attached for stirring. If users wish to up and down the food he has to hold the bar by placing over cooking food placed on fire by exerting physical strength. In case he holds from the wrong side the bar will not help in changing the layer of the cooking food up and down, rather it will be limited to use for stirring the gravy. Exerting the physical strength from the wrong side will hurt the users because of its own pressure. He will ultimately find the holding the bar by placing the bowl inside the cooking food serve for multipurpose of stirring as well ups and down the cooking food for even cooking.

At the time of serving and eating on the ground the food might have the possibility of attracting microbes that may damage the health introduced barrier of large leaves for barrier between cooked served food and ground? Certain insects still able to attack and lowering their chances of being served food not to be spoiled, they thought of raising the platform for keeping the food out of reach from harmful foreign elements. In modern times we call it a dining table. At last, any kind of human was eliminated by designing cutlery.

I am thankful to Prof Dr. Farnaz Nickpour is an inclusive and human-centred design scholar, researcher and educator, and Director of The Inclusionaries Lab for advanced design research at The University of Liverpool, UK. For accepting our invitation for inaugural issue of our nineteenth year issue as Guest Editor. She did her role with complete honesty and it is reflecte in her special issue. Her dedicated team has given her complete support to make this special issue a true international publication.

Lambert Academic publication for celebration of the 150th special issue by publishing a book by compiling editorials "Design For All, Drivers of Design" was translated into eight different languages from ENGLISH to French, German, Italian, Russian, Dutch, and Portuguese. Kindly click the following link for the book. "Morebooks", one of the largest online bookstores. Here's the link to it:
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With Regards
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Forthcoming Issues

February 2024 Vol-19 No-2

Regina Cohen, PhD. – ***Associated researcher, expertise in accessibility, Architect and Town Planner with disability***

G3ict/Smart Cities for All Country Representative for Brazil

CPABE (Certified Professional in Accessible Built Environments)

International Accessibility Consultant

Regina Cohen worked on the Project "Inclusive and Accessible Sidewalks" in São Paulo/BR, promoted by G3ict, University of Washington and the support of Microsoft.

In 2022/2023 Regina worked as Consultant on the Accessibility Projects of Trains Terminals in Rio de Janeiro State, Brazil.

Graduated in Architecture and Urbanism at Federal University of Rio de Janeiro (UFRJ 1981) and has a master's degree in

Urbanism at UFRJ (2000) as well as a PhD Degree in Psycho-sociology of Communities and Social Ecology at UFRJ (2006). She became specialist in Art History and Architecture in Brazil at PUC RJ (1992), experienced with the Architecture and Urbanism field, with emphasis in Architecture and Urbanism.

Post-Doctoral Degree in Architecture (2008-2013) - (scholarship from FAPERJ - PROARQ/FAU/UFRJ) focused on the Accessibility of Persons with Disability to Museums.

Regina Cohen is an associate researcher on accessibility. She coordinated the Research, Teaching and Project Center on Accessibility and Universal Design at Federal University of Rio de Janeiro (Pro-access group, UFRJ – 2000 - 2020). Has been a Visiting Assistant Professor on the Disability Studies Center of Syracuse University in 2014 (FULBRIGHT/CAPES), (Sep - Dec. 2014); Member of Municipal Council of Persons with Disabilities in Rio de Janeiro (COMDEF RIO).

March 2024 Vol-19 No-3

Prof Dr.Ketna Mehta

She is Founder Trustee & Editor (One World), Nina Foundation, a 22 years young NGO for rehabilitation of people with spinal cord

injuries in India. She is an Author of two books; 'Nano Thoughts on Management' & 'Narratives of Courage, Lives of Spinal cord injury survivors in India'.

As editor, 36 issues of 'One World - Voice of people with spinal cord injury' has published since 2001 (www.nina foundation.org)

She is a thought leader on social and inclusive development of persons with disabilities, transformational change and leadership. She was invited to contribute a chapter in the popular book 'Chicken Soup For the Indian Spiritual Soul' !India's very first literary festival by the highest circulated newspaper group The Times of India on 'Disability is a state of Mind.' Her action oriented, innovative and bold opinions on disability has been published in over 100 research papers, articles, book chapters, columns, blogs and interviews in the media. She has been invited as a Guest Editor for Success& Ability's first and only thematic issue on Spinal Cord Injury in 2012, two issues of 'DesignForAll' international publication focusing on 'Improving Quality of life of people with spinal cord injuries' & 'FutureSpeak SCI Rehabilitation' in 2021 & 2019.

She has been a Regional Consultant for WHO's first Research Report IPSCI (International Perspective on Spinal Cord Injury'. For the very first Rehab Exhibition, Nina Foundation was invited as the NGO Partner where a demo workshop of how Scoop Stretchers during the Golden Hour prevents a devastating spinal cord injury. Several Public Forums on spinal cord injury have been curated by her for spreading awareness.Since 25th June 2009 Nina Foundation has initiated a spinal cord injury awareness day. Their grassroots free SCI OPD &multi disciplinary camps have successfully gifted equipments, medicines, hope and solutions for living a life of dignity. In April 2017 was invited by UC Berkeley, California as a faculty jury to evaluate international live student

projects on Universal ReDesign from various countries. She was invited as an Expert Speaker for CIVIL20 (G20) by Rising Flame for 'Women with Disabilities' Panel on 17th June 2023, American Consulate, Mumbai. Nina Foundation is also a PAB Member for SPINE20 (G20) as Speaker & Observer 10-11 Aug 2023.

Ketna is a spinal cord injury survivor since 27 years and lives in Mumbai India.

April 2024 Vol-19 No-4

***Dr.ShatarupaThakurta Roy** has studied Fine Arts in VisvaBharati*

University Santiniketan and did her doctoral research in Visual Culturefrom the Department of Design, Indian Institute of Technology Guwahati.

She is currently working in the Discipline of Fine Arts, Department ofHumanities and Social Sciences as an Associate Professor engaged inteaching and research in the area of Art and design. She is a painter andprintmaker with many national and international exhibitions to her credit.

Per-OlofHedvall*works as Director of Certec, Department of Design Sciences, Lund University, Sweden. His research deals with accessibility, participation, and universal design, with a particular interest in the interplay between people and technology. Working closely with the disability movement, he focuses on people's lived perspectives and how human and artefactual aspects of products, services, and environments can be designed to support people in fulfilling their needs, wishes, and dreams. Hedvall has a background in computer engineering and has a particular interest in people's empowerment and opportunities for participation in their lives.*

Per-OlofHedvall often bases his work on Cultural-Historical Activity Theory. In 2009, Hedvall defended his doctoral dissertation in Rehabilitation Engineering and Design, "The Activity Diamond – Modelling an Enhanced Accessibility", where he developed a model for planned, lived, and long-term aspects of accessibility, as a prerequisite for participation.

New Books

ISBN 978-613-9-83306-1

Sunil Bhatia

Design for All

Drivers of Design

Expression of gratitude to unknown, unsung, unacknowledged, unnamed and selfless millions of heroes who have contributed immensely in making our society worth living, their design of comb, kite, fireworks, glass, mirror even thread concept have revolutionized the thought process of human minds and prepared blueprint of future. Modern people may take for granted but its beyond imagination the hardships and how these innovative ideas could strike their minds. Discovery of fire was possible because of its presence in nature but management of fire through manmade designs was a significant attempt of thinking beyond survival and no doubt this contributed in establishing our supremacy over other living beings. Somewhere in journey of progress we lost the legacy of ancestors in shaping minds of future generations and completely ignored their philosophy and established a society that was beyond their imagination. I picked up such drivers that have contributed in our progress and continue guiding but we failed to recognize its role and functions. Even tears, confusion in designing products was marvelous attempt and design of ladder and many more helped in sustainable, inclusive growth.

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SHERYL E. BURGSTAHLER is an affiliate professor in the College of Education at the University of Washington in Seattle, and founder and director of the university's Disabilities, Opportunities, Internetworking, and Technology (DO-IT) and Access Technology Centers.

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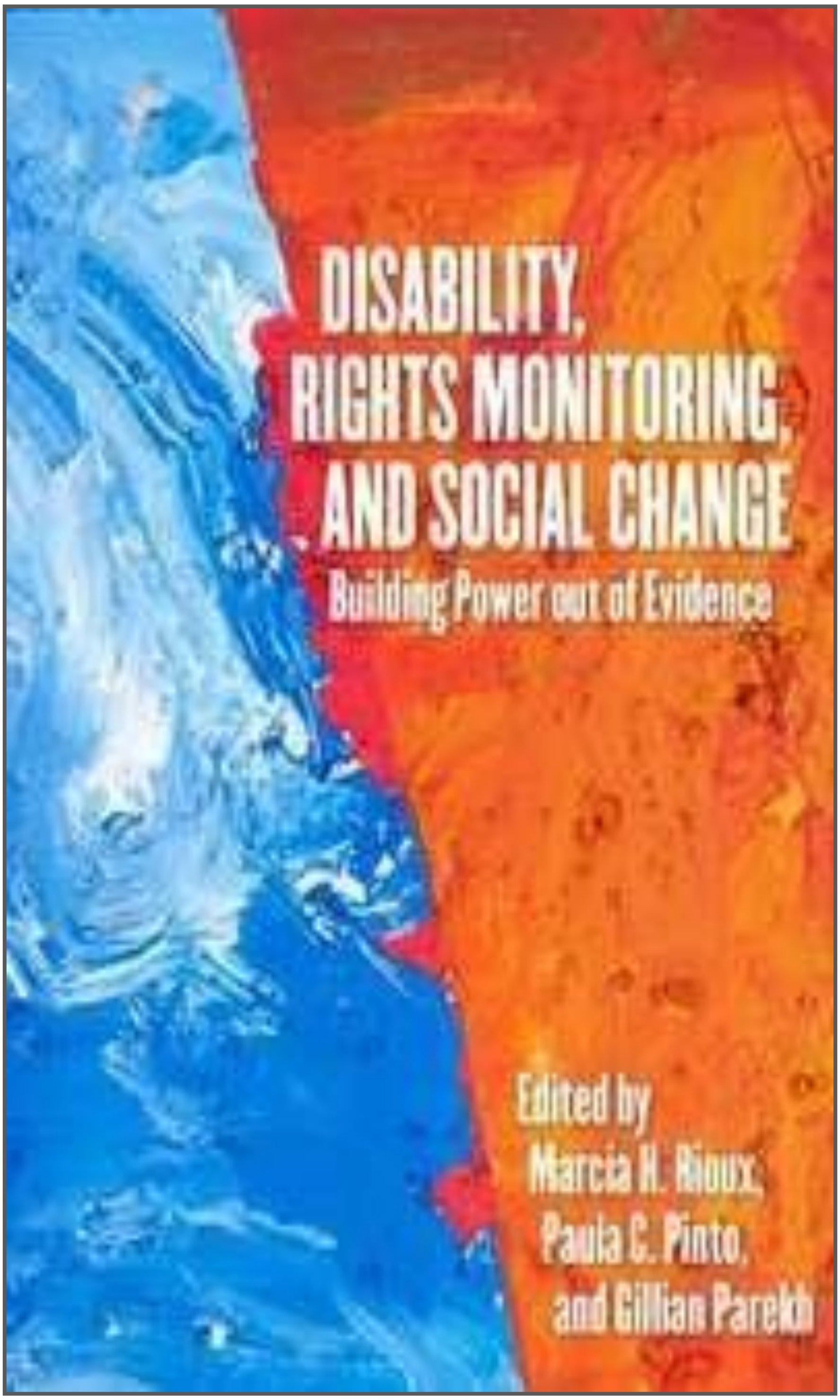

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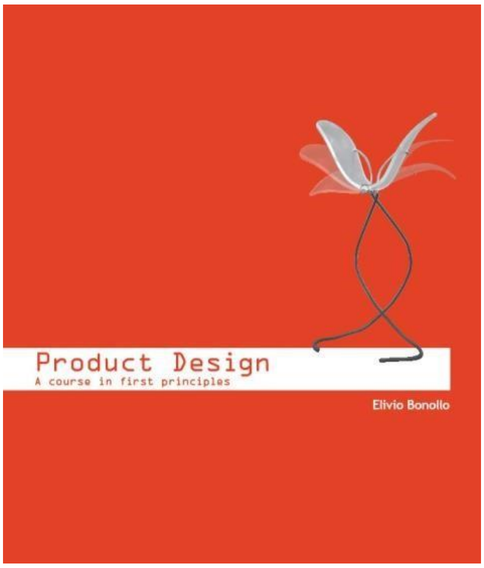

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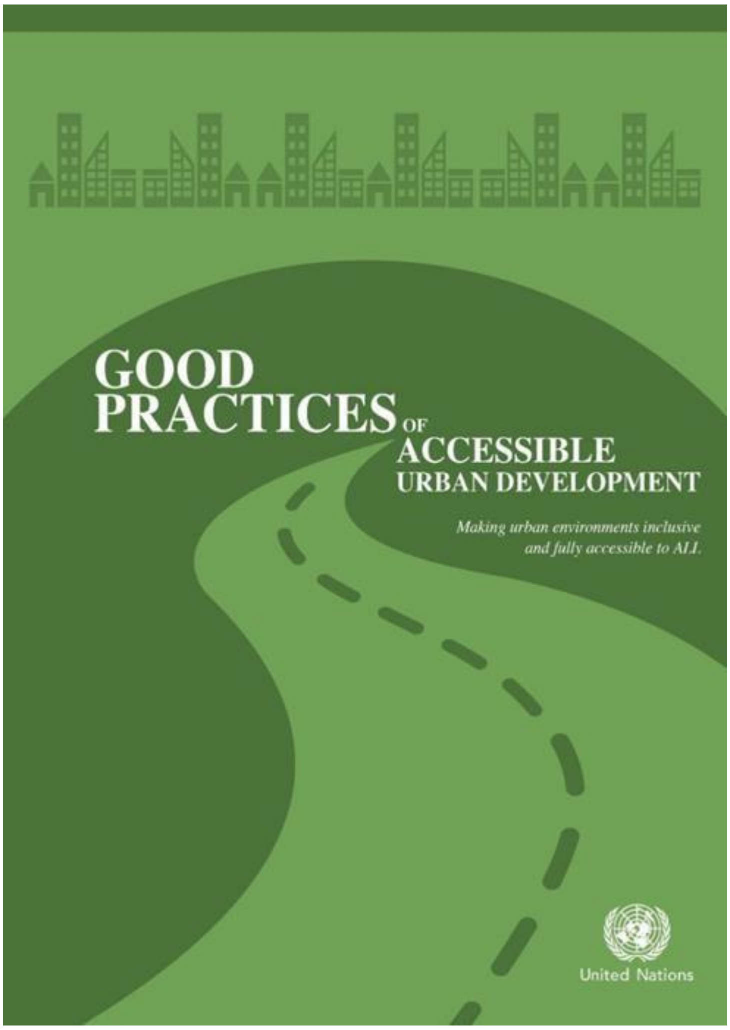
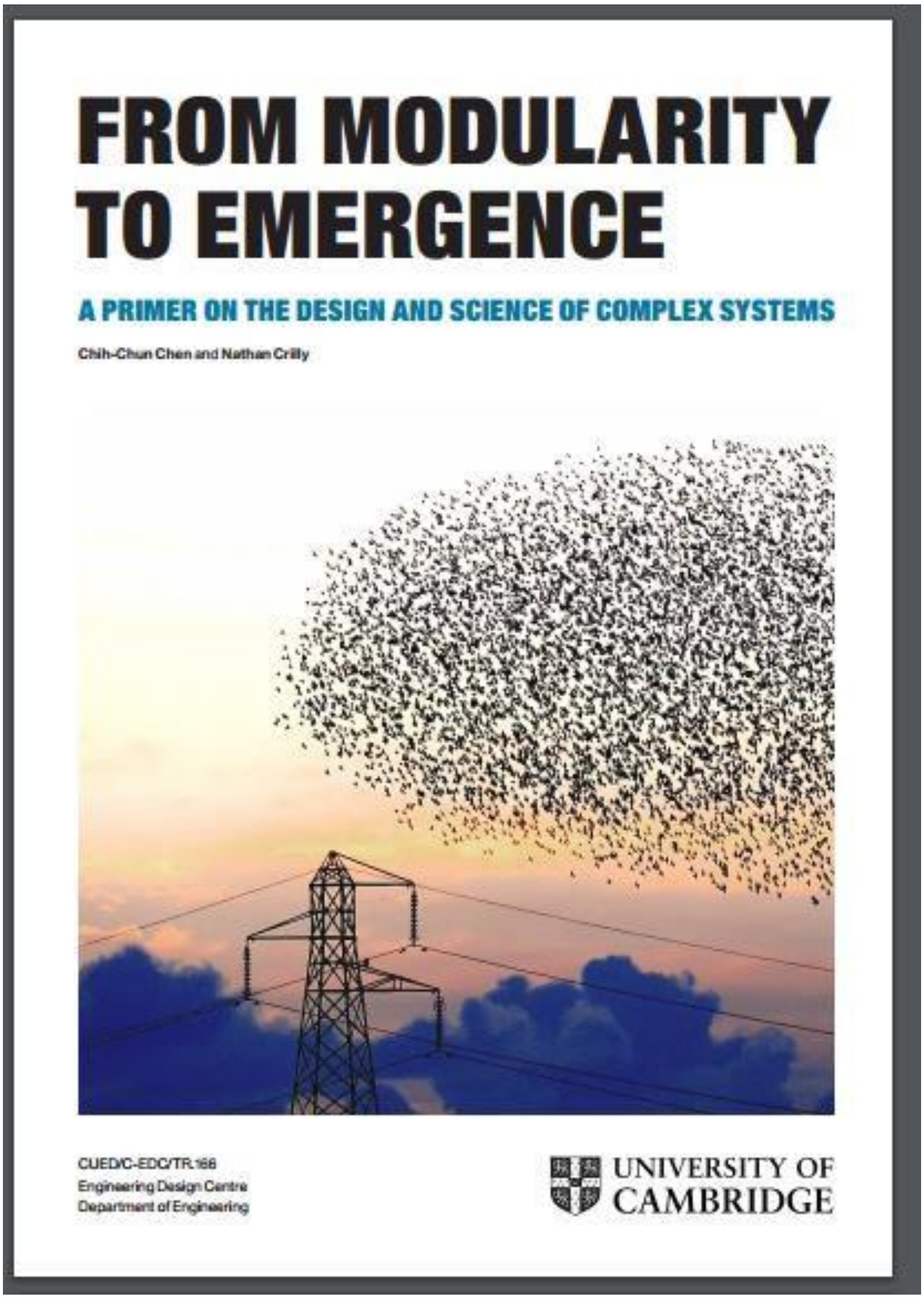


In light of the forthcoming United Nations Conference on Housing and Sustainable Urban Development (HABITAT III) and the imminent launch of the New Urban Agenda, DESA in collaboration with the Essl Foundation (Zero Project) and others have prepared a new publication entitled: "Good practices of accessible urban development".

The publication provides case studies of innovative practices and policies in housing and built environments, as well as transportation, public spaces and public services, including information and communication technology (ICT) based services.

The publication concludes with strategies and innovations for promoting accessible urban development. The advance unedited text is available at:http://www.un.org/disabilities/documents/desa/good_practices_urban_dev.pdf



FROM MODULARITY
TO EMERGENCE

A PRIMER ON THE DESIGN AND SCIENCE OF COMPLEX SYSTEMS

Chih-Chun Chen and Nathan Crilly

CUED/C-EDC/TR.166
Engineering Design Centre
Department of Engineering

UNIVERSITY OF
CAMBRIDGE

Dr Chih-Chun Chen and Dr Nathan Crilly of the Cambridge University Engineering Design Centre Design Practice Group have released a free, downloadable book, _A Primer on the Design and Science of Complex Systems_.
This project is funded by the UK Engineering and Physical Sciences Research Council (EP/K008196/1).
The book is available at URL: http://complexityprimer.eng.cam.ac.uk

Changing Paradigms: Designing for a Sustainable Future

Editors:
Peter Stebbing
Ursula Tischner

CUMULUS THINK TANK
Publication No 1 of the Think Tank Series from the Cumulus International Association of Universities and Colleges of Art, Design and Media

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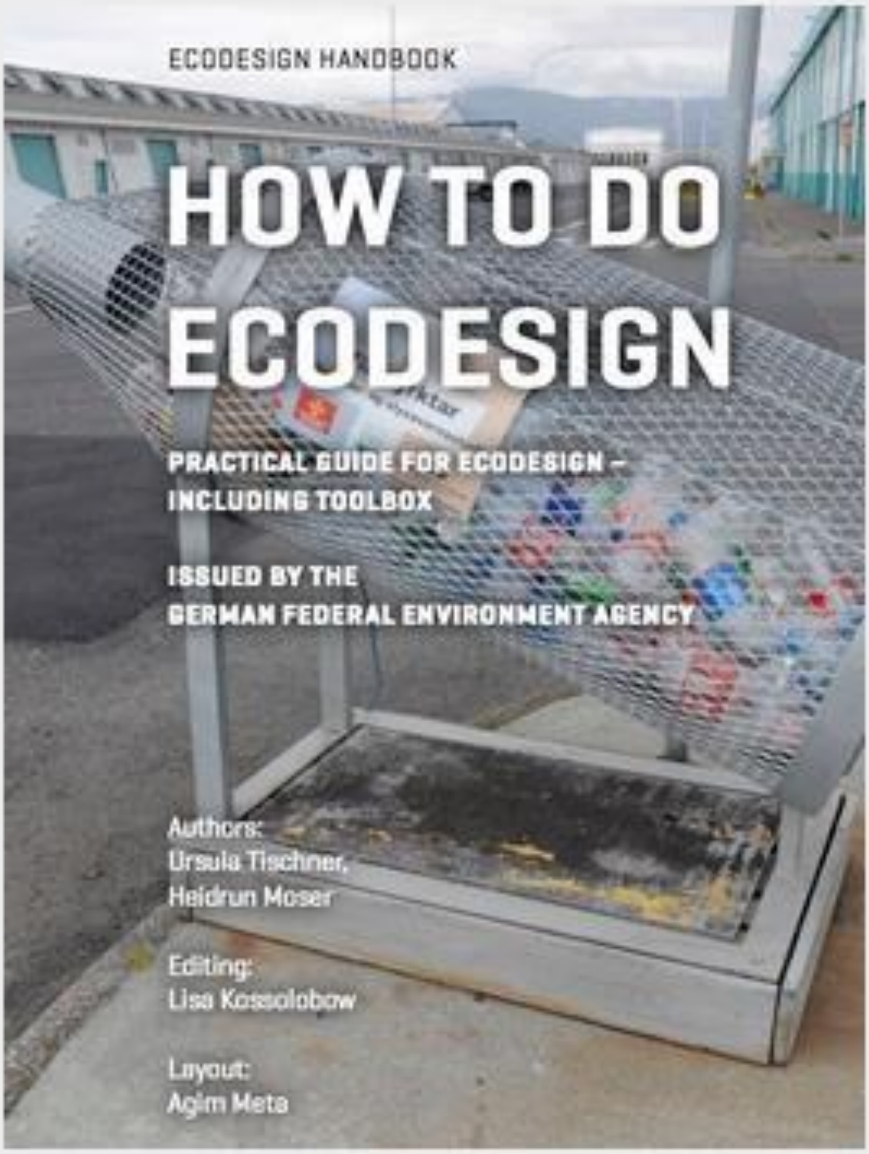
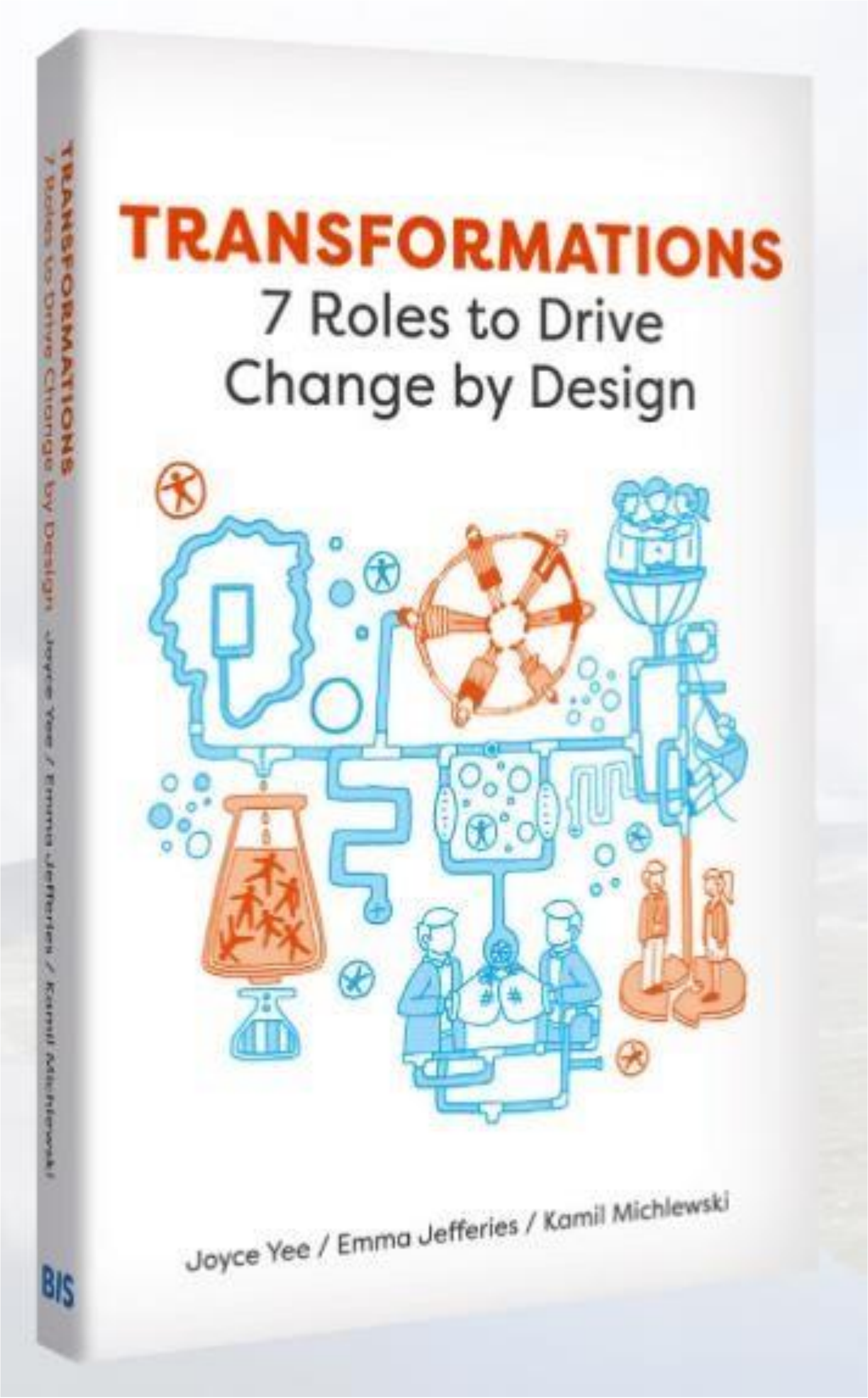
Changing Paradigms: Designing for a Sustainable Future

New iBook / ebook:
HOW TO DO ECODESIGN



Practical Guide for Ecodesign – Including a Toolbox
Author: Ursula Tischner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Change by Design
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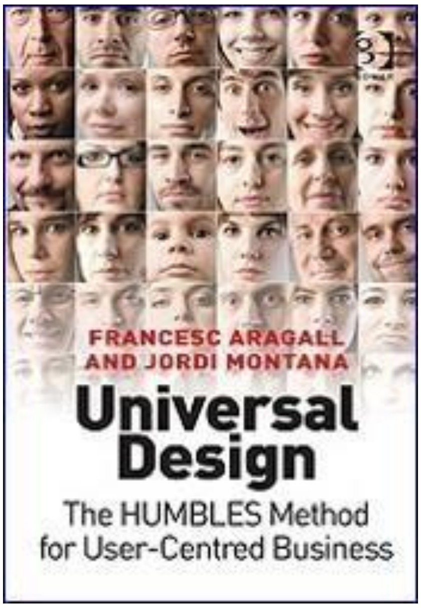
Neo-liberalism, grief and the nation form

Universal Design: The HUMBLES Method for User-Centred Business



“Universal Design: The HUMBLES Method for User-Centred Business”, written by FrancescAragall and Jordi Montaña and published by Gower, provides an innovative method to support businesses wishing to increase the number of satisfied users and clients and enhance their reputation by adapting their products and services to the diversity of their actual and potential customers, taking into account their needs, wishes and expectations.

The HUMBLES method (© Aragall) consists of a progressive, seven-phase approach for implementing Design for All within a business. By incorporating the user’s point of view, it enables companies to evaluate their business strategies in order to improve provide an improved, more customer-oriented experience, and there by gain a competitive advantage in the marketplace. As well as a comprehensive guide to the method, the book provides case studies of multinational business which have successfully incorporated Design for All into their working practices.

According to Sandro Rossell, President of FC Barcelona, who in company with other leading business professionals endorsed the publication, it is “required reading for those who wish to understand how universal design is the only way to connect a brand to the widest possible public, increasing client loyalty and enhancing company prestige”. To purchase the book, visit either the Design for All Foundation website

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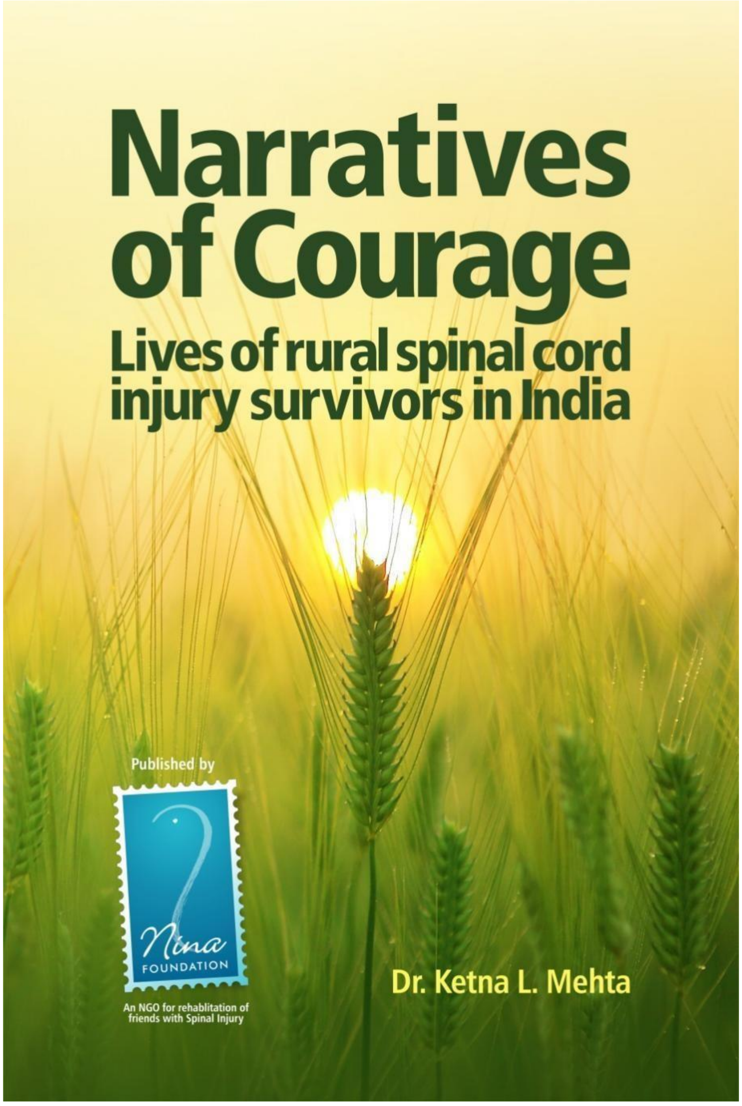

NOW AVAILABLE

Case Studies in Applied Behavior Analysis for Individuals with Disabilities (Second Edition)

Keith Storey, Ph.D., BCBA-D
Linda Haymes, Ph.D., BCBA-D

This book responds to a critical need for highly qualified personnel who will become exemplary professionals because of their advanced knowledge, skills, and experiences in working with students and adults that have varying disabilities, including Autism Spectrum Disorders (ASD). Since Board Certification for behavior analysts was introduced, there has been an expansion of training programs in Applied Behavior Analysis to meet the demands from school districts, health insurers, and families. In spite of these developments, a case studies book has not been available that uses the Behavior Analyst Certification Board Task List, Fifth Edition (BACB) guidelines for educating individuals receiving their BCBA, or for those in the field such as teachers, and service providers. The goal of this book is to fill that need. In this newly revised second edition, eighteen case studies are provided—case studies with complete analysis, case studies with partial analysis, and case studies without analysis. The format, readability, and detailed description of instructional methodology makes this text a valued resource for instructors and behavior analysts responsible for improving the skills of people with disabilities.

Charles C Thomas, Publishing is proud to announce the release of this second edition.

For more information, or to order your copy, scan the QR code below!

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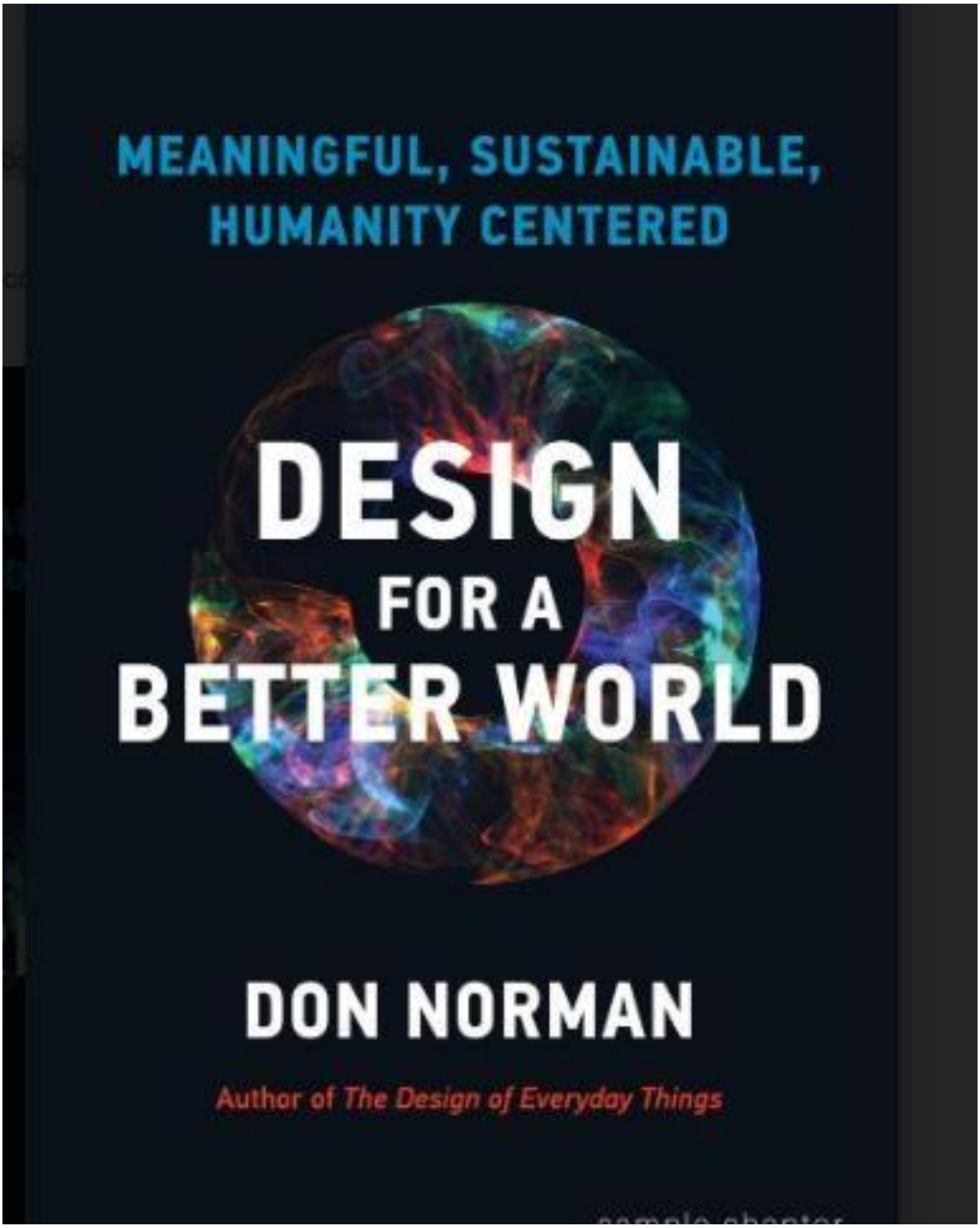
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HUMANITY CENTERED
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FOR A
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DON NORMAN
Author of The Design of Everyday Things

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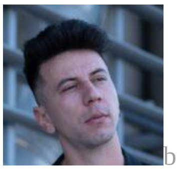
News

1

Zero gravity, equal opportunity: How disabled astronauts are rewriting the rules in space

Individuals with disabilities can enrich astronaut teams and herald a more inclusive future in space exploration



by **Tibi Puiu**

Centra Mazyck, who is an incomplete paraplegic, experienced zero gravity on a parabolic flight aboard AstroAccess's Flight One in 2021. Credit: AstroAccess, Al Powers.

Becoming an astronaut has historically been one of the hardest careers to get into. To say you have to jump through some hoops is an understatement. The last time NASA opened up calls for applications, more than 12,000 tried their luck, but only the best 12 candidates got selected. But for a large fraction of the population, even applying remains a distant dream — for now.

About 16% of the world's population (or 1 in 6 of us) live with a significant disability. Since Soviet cosmonaut Yuri Gagarin became the first person to go to space in 1961, disability has been a solid barrier to space travel.

But times are changing. AstroAccess, a non-profit organization on a mission to promote disability inclusion in space, has set itself

the grand goal of breaking these barriers and sending the first disabled astronauts into space.

Inclusive space exploration

In 2021, AstroAccess took 12 people with disabilities on a zero-gravity parabolic flight, a surreal experience where they experienced weightlessness. The participants, or "ambassadors" as AstroAccess calls them, were split into three teams to perform experiments, each with a different objective. For instance, one group that involved people with varying degrees of sight impairment tested braille displays and tactile sensors.

Another group involved people with either a prosthesis or who need wheelchairs to move. The third group was made up of participants with varying degrees of deafness. These experiments showed that the ambassadors were capable of complying with safety features — such as returning to their designated seats — and even highlighted some of their strengths.

"A zero-gravity flight takes a normal airplane, just a regular commercial aircraft. All the seats are ripped out and there's just padding everywhere. The airplane flies in repeated parabolas, which is why it's called a parabolic flight. And at the top of each of

those parabolas, you experience true weightlessness for about 30 seconds, and then you do it again and again. A typical flight will be anywhere from 15 to 30 parabolas, allowing multiple minutes of weightlessness or what we call microgravity," AstroAccess founder **Anna Voelker** told ZME Science at the **Falling Walls** conference in Berlin.

How a zero-gravity parabolic flight works. Credit: Space Adventures.

The goals of these experiments are manifold. For one, this kind of research will help to guide space agencies to design better, safer spacecraft and space stations. But, most importantly, it's all about showing that some people with certain disabilities can perform their astronaut duties just as well as their non-disabled counterparts.

What experiment did the AstroAcesses ambassador perform?

- The Blind Crew tested tactile graphics for cabin walls to allow both blind crew members and sighted crew members to stay oriented during emergencies and find emergency gear.
- The Blind and Mobility Crews showed that a disabled person can independently get into a launch seat and safely fasten the five-point seat harness.
- The Hard-of-Hearing and Blind Crews demonstrated a system to enable improved speech understanding using Sony headphones and SonicCloud's software that tailors audio to their hearing ability.
- The Deaf crew continued their work on linguistics studies of intelligibility of American Sign Language (ASL) in zero gravity, following research on another parabolic flight and a scuba diving experiment.

Voelker graduated from Ohio State University with a major in science communication and accessibility and a minor in astronomy and astrophysics. They're one of those special people whose enthusiasm is simply contagious. When Voelker talks about improving access to space travel, their eyes light up like the stars in the night sky. I guess you need to manifest that energy in the world when you set out to disrupt how a huge industry such as spaceflight operates. And as one might imagine, it's no easy task.

Shifting the paradigm of what an astronaut looks like

Astronauts are selected from among the most talented and qualified applicants. That's understandable and it's fairly obvious why — critical mission objectives hinge on their ability to perform their tasks successfully and safely. However, there are also hard barriers that disqualify otherwise worthy candidates just because they have a disability here on Earth. And some of these disabilities are not nearly as critical as some people in charge of space programs make them out to be.

"When you have statistics showing at least 16 percent of the world has a disability, it's not acceptable to just exclude massive swaths of the global population when it comes to space travel. We can't allow that. But also, I think a big misconception that we're debunking is this idea that it's too dangerous and it's unsafe," said Voelker.

"Really, when we think about accessibility, what we're talking about is universal design, and that means designing for the widest audience possible. At the end of the day, universal design is redundant design. And what I mean by that, in the space industry, we always want a backup if a system fails. So, if we have accessible design in place, all of a sudden, we have just safer and more effective designs for astronauts with and without disabilities."

On February 24, 1997, an astronaut's worst nightmare happened. Fire had erupted aboard the Russian space station Mir due to a malfunction in the oxygen generation system. The fire cut off access to one of the two Soyuz escape vehicles but also filled the space station with blinding smoke.

"The fire was so enormous and the smoke and vapor coming off this fire site was such that we couldn't see at arm's length — and I could not at that time have imagined that we go on with the mission," recalls European Space Agency (ESA) astronaut Reinhold Ewal, one of six Mir crew members present at the time of the accident.

NASA astronaut Jerry Linenger wearing a respirator following the fire aboard the Mir space station. Credit: NASA.

Amid this chaos, the crew had huge problems finding the fire extinguishers because they couldn't see a thing. But if one of the crew members had been visually impaired, they would have found their way around the station much easier and put out the fire because those are the conditions in which they always operate. In the end, the Mir crew acted professionally and ultimately saved the day — but it was a very close call.

A disability on Earth can sometimes be a natural advantage in space

Voelker argues that even if an astronaut with a disability isn't present on a spacecraft, incorporating accessibility in aerospace still has its merits. For instance, tactile features on the surface of a spacecraft can be used to guide trained astronauts around their ship in the case of an emergency that might shut down the lights inside. Mona Minkara, a blind person and one of the AstroAccess ambassadors, showed how this might work during her parabolic flight when she tested a haptic (vibrating) device that signaled whenever she approached the plane's walls and other obstructions.

"An example I always like to share is the idea that if you had tactile ways to navigate your space station, let's say there's a fire, as there was in the past on the Mir space station, and there's smoke occluding vision or there's an emergency, and the lights go out. All of a sudden, no one can see, but if we had a tactile way to get to that emergency equipment, that could save seconds that are important when it comes to navigating those emergencies," said Voelker, who, besides AstroAccess, is also the founder of SciAccess, which has a similar mission of improving the inclusion of people with a disability in the wider STEM field.

"We see so many examples of this. When we talk about accessibility, what we really mean is, how can we improve our built environments on Earth and beyond it to create opportunities for all people to work, live, and thrive?"

Improving access to space for a wider range of the population isn't like some hollow corporate diversity program. There are important practical and ethical considerations. And in some situations, a disability here on Earth can actually be an advantage during spaceflight. For instance, virtually all astronauts suffer from nauseating space sickness because microgravity confuses the balance mechanism in the inner ear. However, deaf individuals are immune to this problem.

"One example I always love to give is the fact that every deaf person who has ever flown with us has been immune to motion sickness. And this is due to a difference in the inner ear system. It depends on how or why you became deaf, but many deaf people do not experience motion sickness, which is a massive physiological natural advantage because that's one of the major issues astronauts face when first in space: dealing with that motion sickness. And so, here we see just a natural advantage," Voelker said.

"The way they communicate through sign language can also be an advantage. Again, if there was a system failure and your audio comm systems go out, wouldn't it be amazing if all astronauts just knew sign language and had multimodal, multi-sensory ways to communicate and navigate?"

A common type of disability affects mobility, whether it's a missing limb or below-waist paralysis. While this can be a serious disadvantage in Earth gravity, in a zero-gravity environment it gets canceled out because there is no walking — you're just floating.

"I think that folks who are accustomed to navigating the world, not relying on their legs, are actually better equipped to navigate space environments where your legs are just in the way; you don't use them to get around in the way that you do on Earth for most people," Voelker said.

From Paralympics to Parabolas

For NASA to even consider you as a candidate for selection as an astronaut, a person needs to meet four minimum requirements:

Minimumrequirement to qualify for NASA astronaut selection.

🗽 Be a U.S. citizen. There is no age limit.

- **🎓 A master's degree in a STEM field, including engineering, biological science, physical science, computer science, or mathematics, from an accredited institution.**
- **💼 Have at least two years of related professional experience obtained after degree completion or at least 1,000 hours of pilot-in-command time on jet aircraft.**
- **🚀 Be able to pass the NASA long-duration flight astronaut physical:**
- **Distant and near visual acuity must be correctable to 20/20 in each eye,**
- **blood pressure not to exceed 140/90 measured in a sitting position,**
- **and the candidate must have a standing height between 62 and 75 inches.**

When asked about its policy around astronaut candidates with a disability, a NASA spokesperson told us that:

"NASA is committed to ensuring equitable employment opportunities for all personnel and applicants. Individuals with the experience, qualifications, and expertise needed for employment at NASA may apply to be considered for a job, including that of a NASA astronaut. The requirements to be a NASA astronaut have evolved to meet the current needs and goals of NASA missions. When qualifying individuals to serve as an astronaut for spaceflight, NASA looks at what could be required of an astronaut during routine space operations, as well as in potential emergency, life-threatening situations where they may be responsible for the safety of their crewmates. The astronaut selection process determines an individual's suitability for the job and capacity to safely complete mission-specific tasks."

The physical test immediately disqualifies candidates with a sight disability. Although there is no mention of hearing and mobility requirements, people with disabilities in these areas are also immediately disqualified, likely because these are deemed high risk in "potential emergency" and "life-threatening" situations.

However, elsewhere the door is more open, especially with the rapid development of private space ventures.

In 2021, SpaceX launched four civilians to orbit for a three-day mission. One of the crew members was Hayley Arceneaux, a cancer survivor who had an internal prosthesis in her leg. That same year, actor William Shatner, who played the iconic Captain James T. Kirk in the original "Star Trek" series more than half a century ago, reached space during a short flight on a Blue Origin spacecraft. Shatner suffers from tinnitus and was 90 years old when he boarded the flight — not exactly the embodiment of the popular image of a young abled-bodied male astronaut.

"I'm so filled with emotion about what just happened. It's extraordinary, extraordinary. It's so much larger than me and life. It hasn't got anything to do with the little green men and the blue orb. It has to do with the enormity and the quickness and the suddenness of life and death," Shatner said following his touchdown in the company of three civilian crew mates.

"To see the blue color whip by you, and now you're staring into blackness … everybody in the world needs to do this. Everybody in the world needs to see this."

One of the more forward-thinking space operators is the European Space Agency. John McFall, who lost a leg in a motorcycle accident when he was a teenager, was recruited by ESA in 2022 and will soon become the first disabled astronaut. McFall, a surgeon and Paralympic bronze medal winner, is one of 16 ESA astronauts selected from a pool of 22,500 European applicants.

These developments are part of ESA's "Parastronaut Feasibility Project", meant to assess the conditions for including astronauts

with disabilities to work in space. While the psychological and educational requirements are the same across the board for all candidates, this program allows candidates with a lower limb deficiency, a pronounced leg length difference, and short stature (less than 130 cm) to apply.

"ESA is an equal opportunity employer, committed to achieving diversity within the workforce and creating an inclusive working environment. To this end, we welcome applications from all qualified candidates irrespective of gender, sexual orientation, ethnicity, beliefs, age, disability, or other characteristics. Whenever possible, we seek to accommodate individuals with disabilities by providing the necessary support at the workplace. The Human Resources Department can also provide assistance during the recruitment process," an ESA spokesperson said in an e-mail to ZME Science.

Inclusivity in the commercial space era

When it comes to private space companies, each organization can make its own rules on who is allowed to go on a space flight, within legal bounds. "If you're trying to fly with a commercial company, it's right now entirely up to that company to make those rules," Voelker says.

Commercial space travel companies should recognize the importance of accessibility, not just for equity but for market potential, Voelker emphasizes. In the U.S., 24% of the population has a disability, and among those aged 60 and up, it's 46%. Incidentally, older people are usually the wealthiest — the kind of people who could afford to pay a hefty ticket price for a tourism-based trip to space. Ignoring accessibility simply means losing a significant portion of the potential customer base.

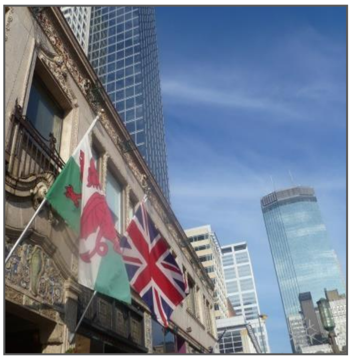
"I always emphasize when talking to those commercial partners that not only is it an equitable, smart, and safe thing to do, it's all commercially viable. And I think we're at a perfect moment in time to be doing it because now is the moment where commercial space is really booming, and those design decisions for future habitats and future vehicles are being made today."

"There are so many advantages to space accessibility, and there are so many advantages to ensuring diversity when it comes to

not only space but also the next generation of scientists and explorers. We need those diverse perspectives, and I think that's really critical to success in science and to success in exploration," Voelker concluded.

We also reached out to SpaceX and Blue Origin for comments on what they're doing to enhance inclusivity in space flight but we hadn't heard back from them up to the time that this article was published.

(Courtesy: ZME Science)



Programme and Events

The annual Conference of the Swedish Anthropological Association (SANT), will take place at Uppsala University, April 24-26

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Diversity & Lived Experience in the City: Politics, Policy, and Practice

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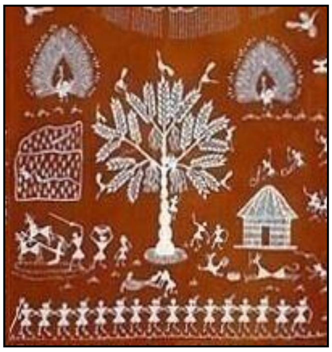

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Prof Dr. Sugandh Malhotra, Indian Institute of Technolgy, Mumbai, India
Email: sugandh@iitb.ac.in

Prof Dr Ravindra Singh, Delhi Technological University, India
Email: ravindra@dtu.ac.in

Special Correspondent:
Ms. Nemisha Sharma,
Mumbai, India
Nemisha98@gmail.com

Address for Correspondence:
13, Lodhi Institutional Area,
Lodhi Road, New Delhi-110 003India.

This journal is published monthly for free for benefits for readers, by Design for All Institute of India,/ 70 Sector-18 Rohini, Delhi110089 (INDIA) and publisher name Dr. Sunil Kumar Bhatia, address A/2/70 Sector-18 Rohini, Delhi-110089 Tel: +91-11-27853470 ,E-Mail: dr_subha@yahoo.com

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ISSN: 2582-8304