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

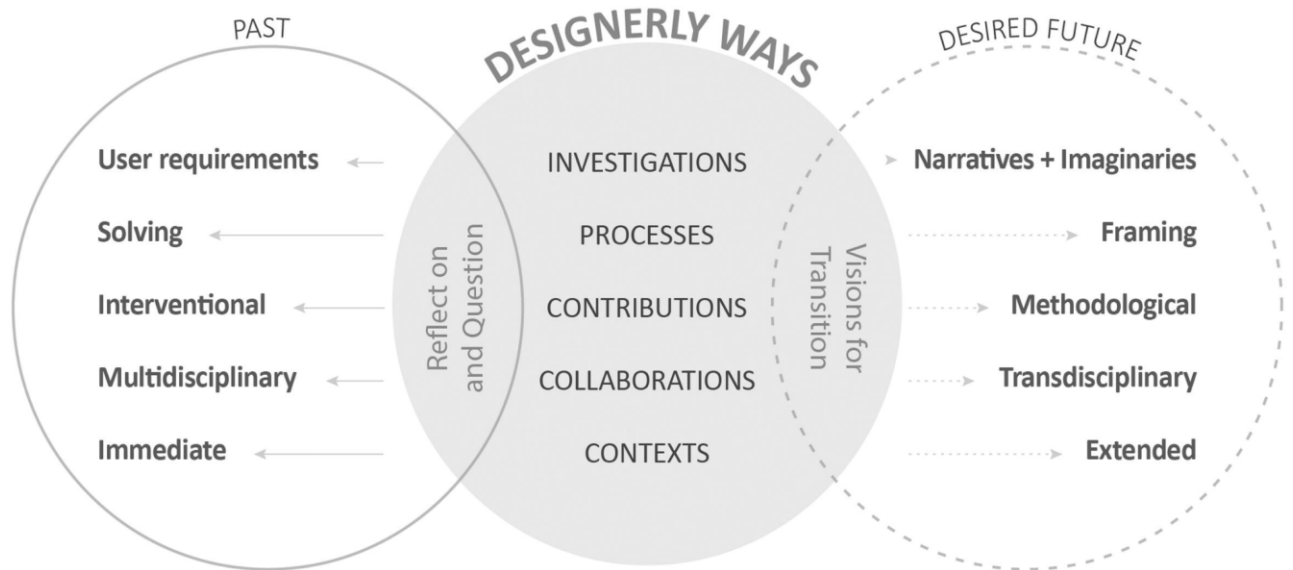
## **1. A Framework for Transitioning Designerly Ways; Interrogating 50 Years of Inclusive Design for Paediatric Mobility**

**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).**



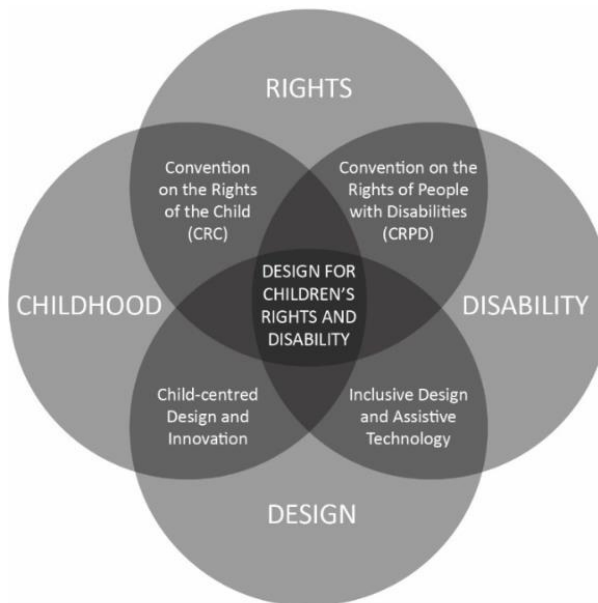
**Figure 1. Reflection-for-Transition framework of Designerly Ways; 50 years of IPM Design.**

## **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.**



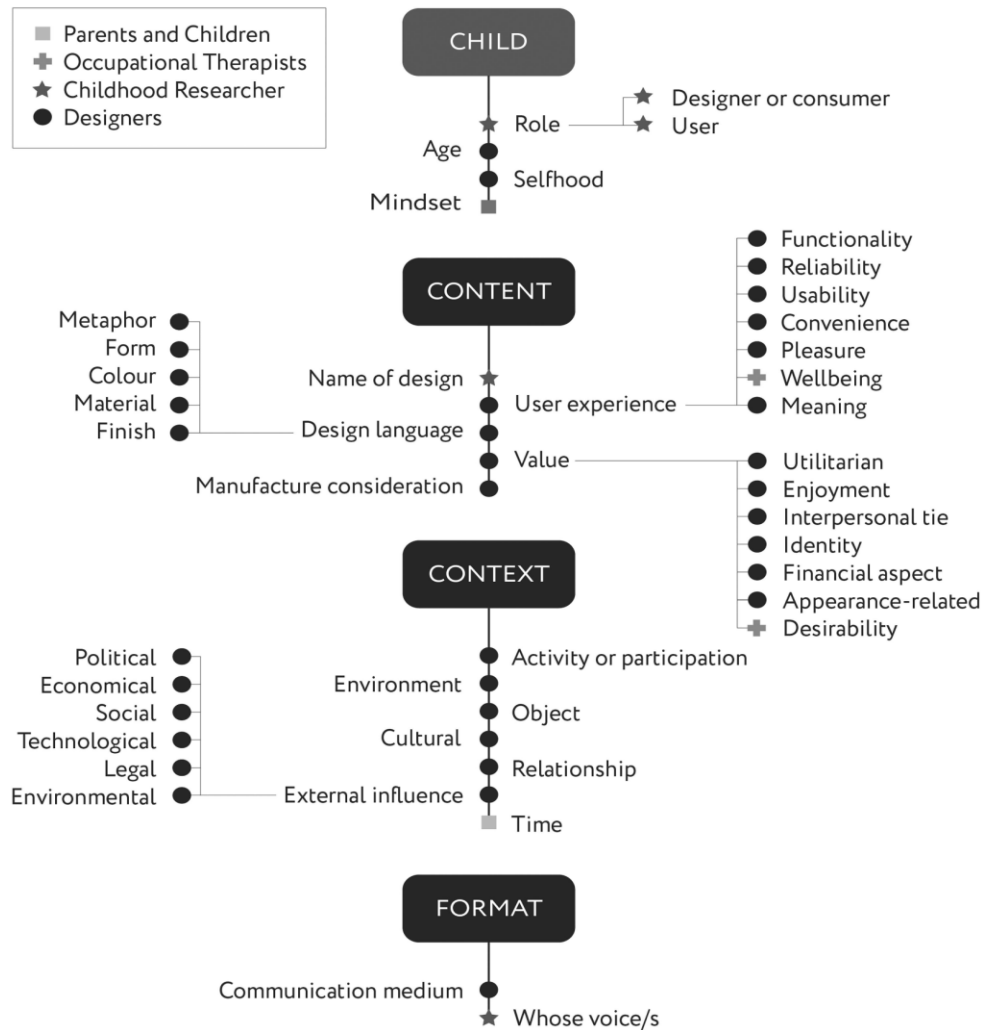
*Figure 2. The relationship between Design and disabled children's Rights.*

### **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.

#### CHILD-CENTRED DESIGN ANALYSIS FRAMEWORK



**Figure 3. Child-centred design analysis framework.**

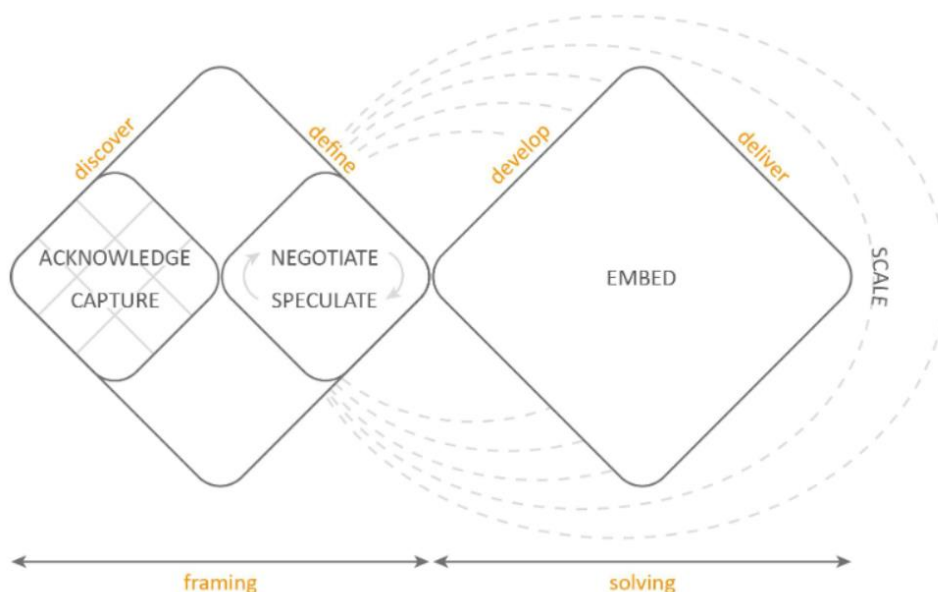
#### 4. Design as an agent of Narratives: A conceptual framework and a first exploration in the context of inclusive paediatric mobility design

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.*

<b>Tension</b>	<b>Applying Design Research in Design Practice</b>
<b>Mindset towards designerly investigations</b>	<b>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.</b>

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<b>Recruiting for child-centred participation</b>	<b>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 &amp; 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.</b>
<b>Documenting insights and requirements</b>	<b>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.</b>

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<b>Timeframes and pace</b>	<b>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 omitted 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.</b>
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<b>Nature of stakeholder collaboration</b>	<b>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 &amp; Nickpour, 2023).</b>
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## **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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