Drivers for Change; Initial Insights from Mapping Half a Century of Inclusive Paediatric Mobility Design

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Abstract. Inclusive Paediatric Mobility (IPM) design is the application of an inclusive design process to create mobility interventions such as wheelchairs, walking aids and exoskeletons, with the fundamental goal of optimising the experience of childhood. The field of IPM has experienced growing attention from a wide range of disciplines and stakeholders, resulting in increased knowledge and the development of new interventions. However, there remains a myriad of issues around the viability, feasibility, and desirability of paediatric mobility products and services, as well as poor documentation of the successes, failures, and approaches used within the field. This paper maps out the history of the field across four categories of contributions i.e. Interventional, Theoretical, Methodological, and Empirical. Key drivers for change identified through the mapping review include Documentation and Representation, Design Approach, Interdisciplinarity, Regionality, and Operational and Market characteristics. These findings offer a starting point for reimagining the future of IPM design.

Keywords: Inclusive Design · Childhood · Mobility · Disability · Assistive Technology · Mapping Review.

1 Introduction to Inclusive Paediatric Mobility

Half a century ago, the widely accepted narrative used to address paediatric mobility disabilities was to 'normalise' children's movement, with walking being the ultimate achievement. This was reflected by the stark lack of independence-promoting inclusive paediatric mobility (IPM) interventions other than walking aids [1]. In the late 1970s, this mentality, and hence narrative, began to shift towards the goal of motivating children to use their most efficient mobility approach to participate in meaningful activities [2]. The field has since accumulated interest from a range of disciplines and stakeholders, leading to increased knowledge and understanding of the need for IPM interventions from an early age [3], as well as the development of new IPM interventions [4]. Despite this, there remains a multitude of issues and barriers around the viability, feasibility and desirability of IPM products, as well as poor documentation of the successes, failures, and design principles and processes used within the field. The purpose of conducting this illustrative mapping review is to capture and illustrate the changing landscape of IPM design and highlight key drivers for change. This in turn,

could help inform the direction and dimensions of a framework aimed at improving the design of IPM interventions of the future. Three distinct aims of conducting the illustrative mapping review are to 1. learn from history; 2. question the present; and 3. reimagine the future. This paper focuses on the former two aims.

2 Understanding IPM Design; What, Why, Who?

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. In the context of commercially available mobility interventions, young children are the most underserved and excluded demographic; they are an 'extreme' user group [5]. There are three predominant approaches to the application of inclusive design [6] and it is important to consider all three in order to build a comprehensive, accurate, and insightful picture of the IPM design landscape. The first is a user-aware design approach which considers and caters for extreme user groups in the design of mainstream products, such as supportive tricycles and go-karts. The second is a customisable/modular design approach which enables mainstream products to be adapted to cater for the needs of extreme user groups, such as ride-on toy vehicles. The third is a special-purpose design approach which caters specifically for the needs of an extreme user group without serving a mainstream market, such as wheelchairs and walking aids.

2.1 Why IPM Design Matters

Significance. IPM is a global need. Independent mobility facilitates children's physical, emotional, psychosocial, perceptual and cognitive development, as well as providing opportunities to make social interactions and increase confidence and participation with peers in everyday activities [7]. Around 90% of brain development occurs during the first five years of life making early intervention and provision of IPM an urgent priority to minimise irreversible developmental delays and likelihood of developing passive, dependent behaviours. IPM interventions are designed to enable independent mobility and hence help children develop to their full potential.

Issues. There is a myriad of unresolved issues around the design of products currently available in the market which act as barriers for incorporating IPM into a child's life. Many IPM interventions exclude children with complex needs and lack up-to-date integrated and assistive technologies, let alone desirability and childhood appeal which has long been the norm in other sectors. Issues around IPM designs can be classified under three meta-levels:

1. Viability i.e. economies of scale, affordability and sustainability [8].
2. Feasibility i.e. usability, technicalities, functionality and features [9].
3. Desirability i.e. acceptability, emotional durability and personal meaning [10].

Opportunities. Emerging initiatives to support the design of inclusive and assistive technologies [11] provide a timely opportunity to develop a framework to equip and inform the next generation of IPM designers with foundational knowledge, processes, and tools; to better steer progress; and accelerate learning in the field globally. Advanced manufacturing techniques combined with the advent of open source movements provides opportunity for full customisation of IPM products and drives rapid innovation at a global scale. The ability to facilitate inclusive and interdisciplinary participation enables: a more holistic perspective on problems and potential solutions; offers co-creation opportunities; gives choice and agency to end-users; and results in products which better match the individual needs of users [12]. From the perspective of health economics, there is also a significant opportunity to build a case for state provision of early years IPM interventions [13].

2.2 IPM Design Stakeholders, Expert Fields and Missing Voices

The field of IPM design resides within the four overarching spheres of Childhood, Disability, Mobility, and Design. The interpretations, definitions and priorities of IPM design vary slightly amongst different stakeholder groups: from providing functional, timely and energy-efficient mobility [2]; to meeting developmental and gross motor milestones [7]; or from providing a safe means of mobility that can track a child's progress and enhance their mobility experience [14]; to enable independence and meaningful participation in life [1]. Each of these priorities reflects different disciplinary perspectives, i.e. Psychology, Occupational Therapy, Design and Engineering, and Parents. The importance of taking a multifaceted approach to IPM has been long established, as has the need for holistic stakeholder input to take into account a range of views and lived experiences [15]. However, this is not fully reflected in the actual design and development of IPM products and there remains numerous scholarly fields, disciplines, experts and stakeholder voices from within and between the four overarching spheres, whose currently missing voices could bring significant value to the IPM design process.

3 Mapping Methodology and Results

An illustrative mapping review is used to categorise contributions by their key features and facilitate evidence synthesis. The data is classified under one of the four types of design contributions outlined in table 1. Data is presented chronologically to allow for identification of trends, clusters, and deserts across all types of contribution. Mapped contributions are then critically analysed to evaluate their quality, significance, and relationship to other contributions on the map. This methodology was selected as it allows various types of design contribution to be plotted at a high level of granularity, using the same categories. Hence, enabling a holistic visualisation and analysis of the IPM field, which is much needed. It should be kept in mind that this is an illustrative mapping review only, and that methodological limitations will likely skew insights. i.e conducting the review in English language only may distort geographic observations.

Table 1. Classification of inclusive paediatric mobility design contributions.

I - Interventional	T - Theoretical	M - Methodological	E - Empirical
New or improved products, services, systems or artefacts. **I.1** Interventions made it to market or are commercialised. **I.2** Interventions remained at concept or prototype level.	Conceptual models, frameworks, policies, principles or important variations on those that already exist (e. g. disability studies).	Novel or refined methodologies, methods, processes, or techniques with enough detail to be replicated by others.	Data sets, surveys, arguments, or findings based on empirical research which reveal formerly unknown insight and analysis of behaviors, capabilities, or interactions with interventions etc.

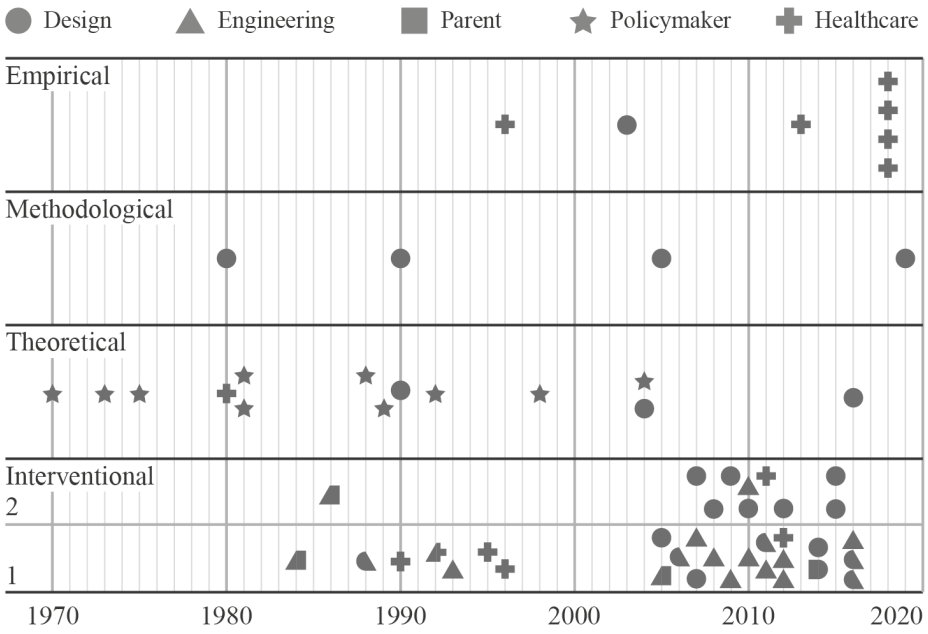

Fig. 1. Illustrative map of designerly contributions to the field of IPM between 1970 and 2020, based on type of contribution and contributor's stakeholder group/s.

The data collection search protocol centred around electronic database searches and manual searches for grey literature, unpublished fieldwork, and artefacts. Inclusion criteria required contributions to: focus on independent mobility (rather than passive mobility); be created between 1970 to 2020; provide record of the context of their creation; relate to at least one child aged ≤18 years with a mobility disability; be specifically relevant to paediatric mobility; be published in English language. The

authors independently determined if contributions met the inclusion criteria. Findings were then shared for further review and input, with four paediatric occupational therapists and four paediatric mobility design engineers. In total, 56 results were deemed eligible for inclusion from electronic database searches. A further five contributions provided by IPM therapists and design engineers were included, bringing the total of contributions eligible for inclusion to 61. Of these, 36 were classified as interventional, 14 were classified as theoretical, four were classified as methodological, and seven were classified as empirical. Subsequently, background information was captured for each contribution. This included year of creation, geographic location, discipline of contributor, and design approach used. Contributions captured by the illustrative mapping review were critically analysed by further investigating the contributor's experience, motivations, methodologies, narratives, and terminology used. Analysing the map highlighted insights and drivers for change in the IPM design field, which have been summarised and discussed under the following five themes.

4 Key Findings and Drivers for Change

Documentation and Representation. The review revealed that IPM design efforts have generally been poorly recorded which may reflect knowledge-sharing barriers [16] or an 'end-result-oriented' mentality. Many of the I.2 interventional contributions were uncovered via media coverage from receiving aspirational design awards; such well-presented inspirational prototypes, videos, or illustrations of final products are represented as indicators of success whilst design processes, failures, long-term measures of success, and empirical knowledge are typically kept in-house, if documented at all. The fact these contributions never made it to being used or commercialised could reflect the complexities and barriers involved with navigating highly regulated healthcare systems. The overall representation of empirical contributions appears skewed towards stakeholders with an academic background which could be due to documentation and dissemination of knowledge being encouraged and allocated more time in academia in comparison to industry.

Design Approaches and Knowledge. Innovation in the field appears to have been incremental, with greater focus given to refinement of existing products. Beginner paediatric power chairs have consistently been the most common type of interventional contribution. None of the recorded interventional contributions were approached with the definition of 'user aware approach' whilst six were approached with a 'modular/customisable approach'. The remaining 30 employed a 'special purpose' design approach to create specific assistive technologies which tend to be targeted at smaller markets, typically resulting in higher costs. The review shows no record of frameworks, processes, or methods relating to the IPM design process. The limited number of theoretical and methodological contributions, specific to the IPM field, leaves little foundation for new interventional contributions to learn from and build upon. This also means, there are no rigorous principles to define, measure, or assess quality and success in IPM design.

Stakeholder Collaboration and Interdisciplinarity. Recorded interventional contributions have mainly been led by engineers or designers with input from occupational therapists and parents but there is little evidence of continued involvement from other disciplines or stakeholders. This could suggest that co-design and multidisciplinary approaches were not effectively adopted in the majority of cases. This could limit the diversity of perspectives, mentalities, and insights from the outset of a project, hence restricting the way narratives and interventions are imagined, and subsequently designed [12]. When contemplating the future of IPM design, it is important to consider beyond the core field, to converge current thinking in broader grounding fields including childhood, disability, mobility, and design. This would require a co-creative, child-centred, and interdisciplinary approach.

Geographic and Regionality. There is a significant lack of novel designerly IPM contributions recorded from developing regions of the world which could be due to limitations of the search strategy, poor documentation of possible contributions, or general lack of contributions from these areas. The majority of recorded contributions come from North America, the United Kingdom, and Scandinavia; this again raises questions around representation and documentation in the IPM design field.

Operational and Market Characteristics. A spectrum of operational profiles was identified. On one end of the spectrum, exist projects instigated by those with a vested personal interest or social responsibility, such as third sector charities, clinicians or family members. These are typically small-scale organisations, cottage industries, or startups motivated by the lack of appropriate existing IPM options. These tend to lack budget or a clearly defined business strategy from the outset. On the other end of the spectrum are large-scale commercial organisations who already mass manufacture adult mobility equipment and have well-established routes to market. The former is a more agile entity with the ability to adapt designs as and when needed, to allow for greater impact for individuals, but can struggle with economies of scale and financial sustainability; they tend to involve a social aspect in their business model such as a subsidised loan scheme. The latter is able to achieve greater impact through reaching larger markets and hence more end-users. However, they can be slow to introduce new products unless financially motivated and generally struggle with affordability issues.

5 Conclusion and Future Research Direction

The illustrative mapping review rendered the field of IPM design as currently lacking a holistic and rigorous reference point to define, measure, assess, and improve the value and impact of contributions. Thus, distinguishing between change and progress is difficult, and leaves little scope to help steer and facilitate future contributions. Designerly contributions to the field have predominantly been interventional and adopted the ‘special purpose’ design approach. Moreover, there is a clear lack of content and continuity across Methodological, Empirical, and Theoretical contributions. The identified key drivers for change include Documentation and Representation; Design Approach and Knowledge; Collaboration and Interdisciplinarity; Geographic and Regionality; and Operational and Market

Characteristics. These findings offer a starting point for reimagining the future of IPM design. They intend to inform future research around the development of a design framework for inclusive paediatric mobility to help steer, improve, and facilitate future product and service interventions.

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References

1. Wiart, L. Darrah, J.: Changing Philosophical Perspectives on the Management of Children with Physical Disabilities. Disability and Rehabilitation (2009)
2. Butler, C.: Effective Mobility for Children with Motor Disabilities (2009)
3. Rosen, L., Plummer, T., Sabet, A., Lange, M.L., Livingstone, R.: RESNA Position on the Application of Power Mobility Devices for Pediatric Users. Assistive Tech, 1-9 (2017)
4. Feldner, H., Logan, S.W., Galloway, J.C.: Why the Time Is Right for a Radical Paradigm Shift in Early Powered Mobility. Disability and Rehabilitation: Assistive Technology Vol 11:2, pp 89-102 (2018)
5. Pullin, G., Newell, A.: Focusing on Extra-Ordinary Users. UAHCI, Coping with Diversity. vol 4554. pp 253-262 (2007)
6. Clarkson, J.P., Coleman, R.: History of Inclusive Design in the UK, Applied Ergonomics 46B, pp235-247(2015)
7. Livingstone, R., Field, D.: Systematic Review Of Power Mobility Outcomes For Infants, Children And Adolescents With Mobility Limitations. Clinical Rehabilitation, 28(10), pp 954–964 (2014)
8. Livingstone, R., Paleg, G.: Practice Considerations for The Introduction and Use of Power Mobility for Children. Dev Med Child Neurol, 56, pp 210-221 (2014)
9. Pituch, E., Rushton, P.W., Ngo, M., Heales, J., Arguin, A.P.: Powerful or Powerless? Children's, Parents', and Occupational Therapists' Perceptions of Powered Mobility, Physical & Occupational Therapy In Pediatrics, Vol 39:3, pp 276-291 (2019)
10. Desmet, P., Dijkhuis, E.: A wheelchair can be fun: a case of emotion-driven design. DPPI '03, pp 22-27 (2003)
11. Global Disability Innovation Hub, https://www.disabilityinnovation.com
12. Wilkinson, C.R., De Angeli, A.: Applying User Centred And Participatory Design Approaches to Commercial Product Development. Design Studies,Vol 35:6, 614-631 (2014)
13. Bray, N., Noyes, J., Harris, N. and Edwards, R.T. (2017). Defining Health-related Quality of Life For Young Wheelchair Users: A Qualitative Health Economics Study. Plos One, 12(6).
14. Soh, H., & Demiris, Y. (2012). Towards Early Mobility Independence: An Intelligent Paediatric Wheelchair with Case Studies.
15. Field, D.: Powered Mobility: A Literature Review Illustrating the Importance of a Multifaceted Approach, Assistive Technology, 11:1, 20-33,(1999)
16. Riege, A.: Three-dozen Knowledge-sharing Barriers Managers Must Consider. Journal Of Knowledge Management, Vol 9 No. 3, 18-35 (2005)
17. Nickpour F., O'Sullivan C.: Designing an Innovative Walking Aid Kit; A Case Study of Design in Inclusive Healthcare Products. In: Designing Around People. Springer (2016).
18. Harries, P., Giacomin, J., Nickpour, F., et al.: Motability Project Report - Scoping Our Future Research Priorities (2015)