

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

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ABSTRACT

Lived experiences and individual interpretations of reality can be effectively communicated through narratives. As such, capturing and understanding narratives can be considered of critical importance in human-centred design, as they form the essence and perspective a design is built upon and are thus essentially embedded into the designed outcome. The role of narratives in design becomes particularly critical when designing with or for end-users whose narratives tend to differ from mainstream dominant societal or disciplinary narratives due to differences in lived experiences. In order to empower such communities and ensure designed entities can be meaningful and desirable as well as usable for them, it is important to proactively uncover, interrogate and incorporate a diversity and plurality of end-user narratives into the design process. This study demonstrates how this could be applied in the field of Inclusive Paediatric Mobility (IPM) Design, by setting out to uncover and interrogate the narratives of nine young wheelchair users aged 4–18 years. 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 is 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 wheelchairs can act as a vessel 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 practice by inclusive mobility designers, stakeholders and policymakers to inform sense-making and opportunity framing processes, to ultimately create more meaningful child-centred healthtech solutions and empower young wheelchair users.

Keywords: Narrative, Design research, Phenomenology, Child-centred design, Inclusive mobility

DESIGN AS AN AGENT OF NARRATIVES

Narratives are embedded within every designed entity (Grimaldi et al., 2013); they frame and shape the essence and perspective from which designs are

created to instil meaning that can transcend functionality and aesthetics (Barthes & Duisit, 1975). The responsibility for deciding which, and more importantly, whose narratives end up being embedded in a designed entity ultimately falls upon designers (Shaw & Nickpour, 2022). Designers typically tend to unconsciously embed and thus reinforce dominant narratives in their work which risks exacerbating marginalisation of users whose narratives differ from the mainstream. By proactively acknowledging, capturing and incorporating a diversity of voices in the design process designers can critically consider and identify the most appropriate and inclusive narratives to utilise, which could result in subverting dominant narratives (Shew, 2021). This can be achieved by mapping the landscape of narrative sources and statuses around the topic of focus (Shaw & Nickpour, 2022).

A narrative ‘source’ represents the origin or author of a narrative, be it an individual, a discipline, or a higher-level societal narrative. When designing with marginalized communities, it is critical to capture representative user narratives, as they portray subjective personal encounters and lived experiences which are internalised through evolving stories of the self (McCabe & Bliss, 2003).

The ‘status’ of a narrative represents its position and influence relative to other narratives around the same topic, ranging from mainstream ‘dominant’ narratives to less common contradictory ‘counter’ narratives, to ‘alternative’ narratives which tend to exist in parallel to dominant and/or counter narratives and could lead to a divergent way of framing a topic (Shaw & Nickpour, 2022).

Harnessing Narratives in Inclusive Paediatric Mobility Design

Engaging with firsthand user narratives becomes critically important in the context of human-centered design, and even more so when designing with marginalized communities whose narratives differ from mainstream societal and disciplinary norms, such as the disability community or children. The case study presented in this paper focuses specifically on the field of Inclusive Paediatric Mobility (IPM) Design, which aims to create mobility interventions such as wheelchairs, exoskeletons, and walking aids for young people who fall into both aforementioned marginalised groups.

It is well established that assistive mobility devices (e.g. wheelchairs) have far more diverse contexts of use than mainstream mobility devices (e.g. bicycles), and it should thus be expected that the meanings and narratives users generate around them transcend the core concept of ‘mobility’ to encompass various areas of life (Lindström et al., 2022; Stenberg et al., 2016). However, the historic lack of exploration of user narratives in IPM design has led to innovation stagnation (Shaw & Nickpour, 2021), emphasising the need and urgency to now explore a diversity of narratives to foster innovation and reimagine or even redefine the way future IPM designs are framed. This requires a shift towards child-centered design, grounded in authentic lived experiences rather than outdated assumptions made by designers and adult stakeholders. Engaging appropriately with user narratives in the context of IPM design holds the potential to advance design justice and optimize design as an agent of children’s Rights (Shaw & Nickpour, 2023) by providing a

gateway for designers to engage, understand, resonate and connect with users on a deeper and more meaningful level.

STUDY AIMS AND RESEARCH QUESTIONS

This paper presents a study that delves into the narratives of nine participants who use a wheelchair as their primary mode of mobility, to identify child-centred themes and ‘dominant’, ‘counter’ and ‘alternative’ narratives which could help frame future IPM design projects. The study addresses three research questions:

1. How could children’s mobility narratives be identified and captured?
2. What are children’s archetypal mobility narratives; what are the high-level themes and within these, what dominant, counter and alternative narratives exist?
3. What are the implications of these narratives in IPM design?

METHODOLOGY FOR CAPTURING AND ANALYSING NARRATIVES

Ethical approval for this study was granted by the University of Liverpool’s Central Research Ethics Committee (ref: 5263) and both written and verbal consent were obtained from all participants and/or their guardians. Nine participants between the ages of 4 to 18 years were recruited for the study from across the UK, representing a range of ages, genders and types of wheelchair use.

Following a critical analysis of appropriate methods for capturing narratives from the intended demographic, it was decided that in-depth narrative interviews would be the most appropriate firsthand way to elicit participants’ authentic personal self-narratives about mobility with richness of detail, whilst allowing flexibility to request elaboration on specific elements of interest (Özyıldırım, 2009). The primary researcher conducted the interviews over a 4-month period via online video calls as and when suitable participants were recruited.

Mobility was used as an anchor topic in the interviews to directly address research question 1; the primary researcher started by asking the participant to share an experience, memory, thought, feeling or opinion around the forms/modes of mobility device/s they use, allowing participants flexibility to choose what they talked about. Narrative interview techniques were employed to encourage expression of subjective lived experiences throughout the interviews (Parczewska, 2017; McCabe & Bliss, 2003). The researcher aimed to simply listen whilst offering minimal encouragers and neutral prompts as the interviewee talked. When they stopped talking, basic language and short questions were used to encourage elaboration on certain details to dig for further information on topics they had previously brought up.

The interviews lasted between 23 to 114 minutes and were recorded using an audio recorder whilst the interviewer also made notes. After completion, the full 9 hours and 27 minutes of interview recordings were transcribed verbatim by the researcher and the nine text transcripts were imported into Nvivo software to undergo a two-stage analysis. The first stage entailed a thematic content analysis to map themes and sub-themes across the transcripts;

during this process, participants' voices were preserved by breaking the transcripts into 'narrative blocks' to ensure full narratives were kept intact and retained their context and meaning, as opposed to eliciting the high-level themes by fragmenting transcripts into individual quotes. The themes were then grouped and merged to create superordinate themes to be used in the second stage of analysis.

The second stage of analysis involved conducting an in-depth interpretive phenomenological analysis (IPA) across the transcripts to explore the complexity of the data in greater detail and capture the finer nuances and meanings lived experiences hold for participants as well as to understand how they make sense of these (Parczewska, 2017). During this process, the high-level themes from the first stage of analysis were used as a structure to investigate if and what dominant, counter and alternative narratives existed around each theme.

NARRATIVE FINDINGS

Tables 1 to 5 in this section specifically address Research Question 2 by curating the five interrelated superordinate themes identified through the first stage of analysis, including: (1) Independence, Freedom and Choice Beyond Mobility; (2) Social Inclusion and Support Networks; (3) Identity, Customisation and Self-Expression; (4) Accessibility and Adaptations; and (5) Resilience and Determination. Each of these themes is populated with dominant, counter and alternative narratives and quotes relating to them.

Table 1. Narrative theme 1: independence, freedom and choice beyond mobility.

Narrative status	Example quotes
Dominant: My chair facilitates new opportunities and adventures.	<p>"A couple of times I went to the skatepark on the ramps. That just felt freeing. I only did the small ramps 'cause I hadn't tried it before and just didn't have the strength to do any other ones, but I did it by myself."</p> <p>"...I went to the beach for the first time this year and was racing on the sand in it and even sat in the sea! That was the first time I went in the sea before, it felt greeeat!"</p> <p>"I want to climb Mount Snowden, I know someone who's already done it in this same type of wheelchair. We climbed the hill near the house and that was pretty good."</p>
Counter: Life as a wheelchair user can be restrictive and emotionally intense.	<p>"It happened more than once in a week where the taxi couldn't pick me up so I remember getting really cross and annoyed and mom had to take me into school to drop me off, and I just remember...bursting into tears because I was so annoyed that they didn't do what they said they were going to do and I didn't feel like they cared."</p> <p>"On a school trip I lost one of the ball bearings from somewhere and so I wasn't able to go around with my friends...so yeah, um, it's kind of held me back when the chair doesn't work, or I don't trust that it's going to work..."</p> <p>"Once I got stuck outside in the freezing cold, and once my wheelchair wouldn't let me move and I was stuck under the sink, and once I was stuck out in the playground and we had to go and get the year 6 teacher and my PE teacher to pick up the wheelchair, get me out of it and pick it up, and carry it back into the classroom!"</p>

Continued

Table 1. Continued

Narrative status	Example quotes
<p>Alternative: I value being self-reliant and in control in my wheelchair.</p>	<p>“Now I can go off and do everything, I know my limits in each different wheelchair...” “I definitely feel like it’s been a freedom; I’ve been able to achieve far more by having to use a wheelchair than I ever would if I was still on crutches or still relied on my legs if they were working. Because when I was ambulant I’d fall over a lot...” “I like to be very independent and do things myself so the only problem with the Hippocampe wheelchair is that I have to be pushed a lot of the time and so it is great but I do find it a bit alienating sometimes because I’m not able to do what other people are doing and I’m not able to umm do it myself.”</p>

Table 2. Narrative theme 2: social inclusion and support networks.

Narrative status	Example quotes
<p>Dominant: Finding a sense of belonging and acceptance is important to me.</p>	<p>“I play games and socialise with people online because I feel like I’m on a level playing field to everyone else there and that’s why it’s what I love to do, it makes me feel part of something.” “...there’d be like an under 19 tournament so every under 19 year old in the country would all gather...we’d all stay over for the weekend and it was like camping with your best friends. It was awesome really. The community definitely helped...” “When I was younger I definitely threw my chair around a lot more, jumped off things just to show off I guess and wheelie a lot more just to be like ‘look it’s cool, it’s not just a mobility aid it’s also like a really cool toy’ which was probably the wrong attitude but it helped with my social circle at the time.”</p>
<p>Counter: People have made me feel excluded and exhibited ignorance of wheelchair etiquette.</p>	<p>“In primary school I wasn’t really accepted for who I, who I was. And people used to make fun of me. For example, the way I drove or they used to push me around when I didn’t want it...Now in secondary school, I feel a lot more accepted. They’re willing to make the changes for me, and adapt and listen to the things I have to say and accept me for who I am...” “I very very quickly got a wheelchair that didn’t have handles on the back because when I had handles on my chair random strangers would just come and push me and I was like ‘what is happening!?’” “The thing that annoys me most is when children, some of my best friends, invite me to absolutely lovely parties that so many of my other friends enjoy, but they’re always somewhere like soft play, so I feel like they could at least put a ramp or do something about soft play that meant someone like me can join, like just put something on the table that’s really fun.”</p>
<p>Alternative: I rely on family, friends and assistants to support me where my wheelchair can’t.</p>	<p>“I don’t really like relying on people but it’s something you definitely have to learn to get used to; asking for help and needing help.” “At the moment I have to stop outside for mum to hose all the wheels off before I’m allowed in the house...” “Mum helps if it needs maintenance but I get help from my mum, my dad, my brother, my granny and grandad, my teachers, my classroom assistant, that’s about it - they just push me when I get tired...”</p>

Table 3. Narrative theme 3: identity, customisation and self-expression.

Narrative status	Example quotes
<p>Dominant:</p> <p>My wheelchair is like a part of me so how it looks affects how I feel about myself.</p>	<p>“I feel like when you’re a kid it’s kind of like a toy, it’s like I just have this scooter I live in or like a skateboard that I get to sit on, whereas now it’s more a piece of me and a piece of my identity...in terms of the fit of it as well, if you wore heels that were too big you wouldn’t feel as confident as if those heels fit snug and you could snap down that hallway y’know...”</p> <p>“For my prom I had like a purple dress. And I remember getting purple fairy lights and putting them around the wheels and things like that. So yeah, I think making it kind of not an accessory, obviously, it was a necessity, but to be able to accessorise it in some way was really important, especially at a younger age..”</p> <p>“My wheelchair is yellow and pink, I picked them because they’re my favourites. It’s got glitter too, I like how it looks. I feel happy in my wheelchair. Belle and the good dinosaur are on my wheels with my name too.”</p>
<p>Counter:</p> <p>Wheelchairs need to be more customisable; no single wheelchair is suitable for everything I’d like to do.</p>	<p>“All my wheelchairs do different things so if I just had this one [points at manual chair] I couldn’t do very much. There’s not like A perfect wheelchair... Both combined would be perfect.”</p> <p>“This wheelchair can go higher up, but it can’t go down to the floor and put its legs out straight like my other one could. But that one couldn’t lie down so there’s a bad difference.”</p> <p>“If we’re going somewhere muddy I use ‘the Beast’ because the wheels are a bit chunky, but if we’re going shopping or something I take the Permobil because it’s easy to move. Like having the choice between different pairs of shoes.”</p>
<p>Alternative:</p> <p>My relationship with my wheelchair could be improved by features unrelated to mobility.</p>	<p>“A lot of wheelchair covers for the rain have one big cover to go on top like a buggy cover but I hate that. It’s the joystick part of the wheelchair most vulnerable to rain so I want a little cover that just goes over that instead and it’s not too much of a problem.”</p> <p>“These armrests are perfect for hot weather [sarcasm]. Black plastic, black seating, black headrest, black wheelchair. So I burn myself on my armrests when it’s sunny!”</p> <p>“I’d like a wheelchair that could last as long as you live so you never have to get rid of a wheelchair. Maybe just, like, change its seating.”</p>

Table 4. Narrative theme 4: accessibility and adaptations.

Narrative status	Example quotes
<p>Dominant:</p> <p>The world needs to be more inclusive and understanding of wheelchair users.</p>	<p>“I can’t go into people’s houses like I used to be able to crawl up stairs to a front door, so I can’t go over to friends’ houses anymore.”</p> <p>“Dropped curbs were there but people park cars in front of them so it was impossible to get up on the pavement alone.”</p> <p>“I would love to live in a world where it’s a lot easier to get around. Like shops could be more accommodating with ramps and lifts, and I just think that people need to understand more and be more accepting of the problems I face in my wheelchair.”</p>
<p>Counter:</p> <p>Wheelchairs need to cope better with navigating obstacles and challenges in a range of environments.</p>	<p>“I had this as my main one for a bit but it’s only good on flat land like concrete. So, I couldn’t go on grass or gravel and if we went to a restaurant we couldn’t sit outside because it wouldn’t move. It’s good on flat but anything else like a curb, it couldn’t get up...”</p> <p>“I like going to the beach in it... well, it doesn’t really go onto the beach much, it goes next to the beach.”</p> <p>“If the sensors get wet the chair will fail and won’t work. They can get a little damp in light rain but if there’s a downpour then you need to get out of it...”</p>

Continued

Table 4. Continued

Narrative status	Example quotes
Alternative: Adaptations or using other equipment can improve access and enjoyment.	<p>“I like going to the farm, it’s very muddy and fun...I get out of the car and I’ve got a trike, sometimes I go in that or sometimes I go in my wheelchair. My trike is pink and has hand-pedals like a mixing bowl. It’s very good for going in the mud and there are loads of puddles which I enjoy going through up there...”</p> <p>“Something fun I did was surfing...they’ve got this seat I sit in then they take me into the sea, it’s a bit like a club, I like going into the water.”</p> <p>“We went to the allotments yesterday and collected leaves that had fallen from trees. They’re different colours, we just collected them. It was cold so I needed my CosyToes to keep warm.”</p>

Table 5. Narrative theme 5: resilience and determination.

Narrative status	Example quotes
Dominant: I can’t rely on healthcare systems and mobility services to just do what’s best for me.	<p>“I was diagnosed with SMA when I was about 18 months so they knew I wouldn’t be able to walk but in this country the NHS only gives you a wheelchair when you’re five years old and my parents thought there’s no point waiting till I was five - I’ve only just turned six now and I don’t want to be pushed around in a buggy! So they got me a wheelchair themselves.”</p> <p>“The wheelchair services, the first one they didn’t deem that I needed because I was using crutches and they thought that that was fine. So yeah, the first few [wheelchairs] were kind of funded by my family, which was kind of fine at the time because they were under £100. But obviously after that they were like £1000s. So we had to look at more funded options.”</p> <p>“Experiences with wheelchair services haven’t been great. For example, once my lateral support fell off, and I can’t hold myself up so without that I fall over. If we didn’t have our own wheelchairs I’d have been without one for six months!”</p>
Counter: Overcoming and learning from challenges can boost my confidence.	<p>“I’ve learnt with age that wheelies are actually useful, they’re not just a trick. It’s not just showing off, sometimes you really do need to be able to get on your back wheels to get over gravel, grass, cobbles...”</p> <p>“If my dad’s like ‘you cannot get through’ and the gap’s just like so small and I say ‘I can get through there’ and he looks at me like ‘I don’t think you can actually get through’ and I go through it and what happens? I’m through it.”</p> <p>“Screws used to come out all the time...so I started carrying the toolkit, but then the next chair that I got, I made sure it was all welded and there weren’t many parts that could go wrong.”</p>
Alternative: I want to raise awareness and also advocate for representation.	<p>“Something I’ve had to teach my family and friends, at home if I’m in the way and they just want to get past they used to try and just move me out of the way and I know it’s just done from a good place but at the same time it’s like you can’t do this. So there are lots of ‘ask first’ scenarios they’ve learnt about...”</p> <p>“...I always smile when I see someone in a programme or a book that has a wheelchair or has a disability...They don’t usually think that including people with other things as main characters can be inspiring...”</p> <p>“When I go around my classroom I move a lot of tables because I just go around and collide with chairs because people don’t consider or respect to tuck a chair in.”</p> <p>“It’s annoying because I wish sometimes with companies or people like that I could just get a magic wand...and then transfer all your problems and things onto them so that they finally understand.”</p>

DISCUSSION AND IMPLICATIONS

The synchronous existence of dominant, counter and alternative narratives around each narrative theme offers a comprehensive insight into the diverse and intricate experiences of young wheelchair users whilst collectively painting a vivid picture of the multifaceted challenges, triumphs, and aspirations that shape their lives. The first theme, ‘Independence, Freedom

and Choice Beyond Mobility’, encapsulates the nuanced relationship between the wheelchair and the user’s sense of agency, revealing both the empowering opportunities it offers and the potential emotional constraints it can impose. Similarly, the second theme, ‘Social Inclusion and Support Networks’, underscores the pivotal role of social connections in overcoming barriers and fostering a sense of belonging, whilst also shedding light on the painful instances of exclusion and lack of awareness about wheelchair etiquette. In the third theme, ‘Identity, Customisation and Self-Expression’, the intersection of self-identity and wheelchair customisation becomes apparent, revealing how the design and appearance of the wheelchair intertwine with the user’s perception of self. The fourth theme, ‘Accessibility and Adaptations’, delves into the societal challenges faced by wheelchair users, emphasising the equilibrium between needing more inclusive environments, more adaptable wheelchairs, and adaptations that can enhance accessibility. Lastly, the fifth theme, ‘Resilience and Determination’, showcases the users’ determination to overcome obstacles, highlighting their autonomy in advocating for their needs and raising awareness about their experiences. The intricate interplay of personal narratives and societal dynamics highlighted through the study findings, underscores the imperative for a holistic child-centred approach to designing mobility solutions that truly cater to the needs, desires, and aspirations of young wheelchair users.

As well as offering insights around the lived experiences of young wheelchair users, the findings from this study could also serve as a foundation for co-design sessions in the IPM design process, highlight specific areas for further design consideration, and ultimately empower young wheelchair users in the IPM design process. It is crucial to consider how the meanings and narratives attributed to wheelchairs are impacted by the necessary evolution of context, function, and experiences that occur both long-term and short-term throughout the product and user’s lifetime, particularly throughout childhood. An enhanced narrative approach to user journey mapping could help understand the complex matrix of factors contributing to such changes, including progression of user’s condition, physical growth, development of psychosocial characteristics and self-identity. Creating inclusive mobility solutions that adapt and meet the evolving narratives of children and young people may involve moving away from a single solution-focused product and towards one that can be adapted and used according to the specific requirements and desires of users at a given stage in their mobility journeys.

CONCLUSION

This study identified dominant, counter and alternative narratives around five high-level themes relating to young wheelchair users’ mobility, including: Independence, Freedom and Choice Beyond Mobility; Social Inclusion and Support Networks; Identity, Customisation and Self-Expression; Accessibility and Adaptations; and Resilience and Determination. The study illuminates the complexity, duality and dynamicity of end-user narratives in this context and highlights how wheelchairs can act as a vessel for narratives

which transcend the concept of mobility, encompassing a deeper sense of identity and selfhood, enriched with values, feelings, and opinions related to various areas of life. The narratives and insights identified through this study could be adopted in practice by IPM designers, stakeholders and policy-makers to inform sense-making and opportunity framing processes to create meaningful child-centred solutions.

ACKNOWLEDGMENT

This research was supported by the Hugh Greenwood Fund for Children's Health Research. The authors would like to sincerely thank the nine young people who kindly and honestly shared their lived experiences for this research.

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