

Title: Wheelchair and Seating Provision a Gateway to Freedom

Running heading: Wheelchair, Seating Provision a Gateway to Freedom

Article category: Research Paper

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Declaration of interest: The lead author received a fellowship from the Health Research Board to conduct the ethnographic study mentioned in this paper in relation to part one of this study.

Acknowledgements: Thanks of all those who participated in this study. Thanks also to MSc (PQ) Occupational Therapy Graduates Kate Cleere, Geraldine Cleary and Sinead O'Sullivan for their contributions.

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Abstract

Aim The meaning of wheelchair and seating assistive technology and the impact inappropriate provision has on people's lives from a service user's perspective within an Irish context is highlighted. There is a dearth in evidence examining the process of wheelchair and seating provision and the interconnectedness between satisfaction, performance and participation from an equality and human rights perspective. **The purpose of the study is to investigate wheelchair service users' perspectives of wheelchair and seating provision in Ireland.**

Method This is a mixed-methods study with an exploratory sequential design that includes two phases. During phase one, wheelchair service users were invited to take part in qualitative in-depth semi-structured interviews, which were thematically analysed and formed part of a larger ethnographic study involving multiple stakeholders in sustainable wheelchair and seating provision strategy development. In phase two, an on-line Survey Monkey questionnaire was distributed to obtain a wider overview of wheelchair service provision from a wheelchair service users perspective. Data obtained from the closed questions and content analysis for open comments was analysed descriptively for this phase.

Results Eight wheelchair service users agreed to participate in the interviews and 273 responded to the online survey. Thematic analysis and questionnaire frequency and content analysis revealed the vital meaning of wheelchair and seating assistive technology provision. However, bottlenecks within the system affect daily living, with qualitative data highlighting the obstruction to experiences of independent living from initial appointment to wheelchair breakdowns during daily living.

Conclusion Appropriate wheelchair and seating assistive technology provision is a basic human right, supported by the essential and embodied nature of the wheelchair as demonstrated through the wheelchair users' perspective throughout this study. These findings highlight the impact of ad-hoc services on individual freedoms and how the overall pace of the system affects a person's ability to organise their time as an equal member of the community across the lifespan. A national review of wheelchair and seating assistive technology

provision service is called for, giving consideration to access to service, assessment and delivery, follow up and management, education and training.

Keywords: Human Rights; Assistive Technology; Wheelchair Provision; Policy Development; Daily Living.

Introduction

Appropriate provision of wheelchair and seating assistive technology is an essential prerequisite to community mobility and active participation in daily life for many people with mobility impairments. Research to date on wheelchair and seating assistive technology generally either explores users' satisfaction with and experience of their wheelchair or mobility device [1–3], or how the use of devices affects performance, active participation and quality of life [4–8]. To the authors knowledge, few studies have examined the process of wheelchair and seating provision and the interrelation or interdependence between satisfaction, performance and participation to empower people with mobility impairments to reach their potential from an equality and human rights perspective [9,10]. This paper presents the results of a mixed-methods study that explored the wheelchair service users' perspectives of wheelchair and seating provision. The paper highlights the meaning of wheelchair and seating assistive technology and the impact inappropriate provision has on people's lives from a service user's perspective in an Irish context.

Literature review

The context in which wheelchair and seating provision infrastructures have developed is unique and appears to be dependent on the social, environmental, economic and political governance. Service development is also influenced by the innate cultural relationship and value societies have with equality and participation for all [11–13]. Few countries support direct and specific policy in relation to the 'modernisation' of wheelchair and seating provision [14,15] with many providing more generic assistive technology policies and services [16–18]. As an example, the Republic of Ireland has no specific wheelchair and seating provision policies, with service delivery management processes imbedded within an aids and appliances funding category, alongside hospital beds, commodes, shower chairs and communication aids [19,20]. Evidence suggests that Irish wheelchair services are ad-hoc, with access to services, assessments, delivery processes, follow up reviews, repairs and maintenance lacking uniformity across the country [19, 20]. In addition, the availability of education programmes with a specific focus on wheelchair and seating assistive technology are limited [9].

The meaning of wheelchair and seating assistive technology provision to service users

The ability to roll, sit, stand and walk are considered to be major milestones in human development. Mobility and movement are essential to human function, assisting with the overall development of body structures [21]. Therefore, appropriate wheelchair and seating provision is key to survival for wheelchair users. Wheelchair seating and assistive technology is seen as 'a freedom of mobility and independence' (22, p. 701). It is an essential prosthetic device, significant when facilitating active life roles for both individual users and their carers.

Evidence suggests that poor and inappropriate provision could have devastating effects on the individual, causing increased physical impairment, pain, depression, isolation and death [8,23,24]. It is difficult to compare the exact meaning of wheelchair seating and assistive technology to other assistive technology, as its usage is required at a primary level for posture and mobility prior to accessing many other aids for independence. This concurs

with the Convention of Rights for Persons with Disabilities [25] which places responsibility on governments to prioritise the provision of assistive technology for personal mobility. Internationally, an urgent need for better policies advocating for access to assistive technology focusing on universal design, independence, social participation and health/wellbeing for all has been highlighted [26–29]. Stakeholders have also identified the need for strengthened evidence-based, integrated, adequately-resourced wheelchair services supported by policies, a range of appropriate wheelchairs, and adequate personnel [30]. It is imperative that service user involvement and influence is included in research to support these policies while keeping people at the centre of the assistive technology systems [31,32]. Rousseau-Harrison et al. [5] stressed that it is important that those involved in provision had a ‘better understanding’ of the impact that wheelchair prescription had on life habits in order to plan and deliver appropriate wheelchair and seating services.

This research aimed to explore levels of satisfaction, experiences and the meaning of wheelchair and seating assistive technology provision from a service users’ perspective.

Methods

This mixed-methods study used an exploratory sequential design [33], which included two phases presented using the GRAMMS reporting guidelines [34]. The first presents thematic analysis of qualitative in-depth semi-structure interview with wheelchair service users following COREQ reporting guidelines [35], which formed part of a larger ethnographic study involving multiple stakeholders in sustainable wheelchair and seating provision strategy development [9]. In addition, to gain a broader overview of wheelchair service provision for a wheelchair service users perspective, the second phase presents the results of an on-line survey using the CHERRIES reporting guidelines [36] (See Supplement I).

Phase One

The first phase was drawn from an organisational ethnographic study which utilised a soft systems approach [37] incorporating participant observation (to identify key stakeholders), individual semi-structured interviews and a series of collaborative workshops [9]. A research partnership with one specialist wheelchair and seating service in the Republic of Ireland was established as the host institution and acted as a location to connect with participants. The qualitative research design was chosen to study the multiple complex characteristics of wheelchair and seating provision from a stakeholder perspective, tuning into the uniqueness of human beings, their interactions, and their effect on a given system [38]. The semi-structured interview schedule drew from political reasoning tool (the pADL -political Activities of Daily Living) framework and Capra’s [39] concepts on reflective consciousness. Following a stakeholder identification process forty-two participants were sent invitation cards by posts, followed up by a phone call requesting participation. A total of 35 stakeholders were recruited, including service users (n=8), service providers (n=22), suppliers and manufacturers (n=3), regulators (n=1) and policy makers (n=1). For the purpose of this paper, phase one focuses on the eight service user participants only, representing a convenience sample of people across the life course with varying diagnoses and experiences of wheelchair and seating provision services. Parents provided representation for children below 18 years of age.

The interviews conducted by the lead author focussed on participants’ experiences of using the wheelchair and seating services, indicating, for example, their level of involvement, issues that are motivating or frustrating, and what changes they would they like to see, if any. The first two interviews served as pilot interviews (see Supplement II) and were included in the data. Interviews were scheduled for ninety minutes at a time, at a place convenient to the participant. Interviews were audio-recorded and transcribed verbatim. Thematic analysis was

used to interpret participants lived experience and identify themes. Braun and Clarke [40] provide a description of a 6 phase process for thematic analysis which was used during the analytical process, creating a 'rough coding' system before the data items could be examined more closely to 'define and refine' themes using a selection key data extracts to present a coherent representative narrative. Member checking occurred with participants reviewing interview transcripts and preliminary findings.

The study used a variety of trustworthiness strategies. Recognising issues of reflexivity and positionality the lead researcher kept a reflective diary to represent biographical and philosophical perspectives. The inclusion of the perspectives of multiple stakeholders strengthened trustworthiness when capturing the multiple perspectives of participant narratives [41]. In terms of the lead author's positioning, she is a university faculty member with interest and experience in the subject of wheelchair and seating provision, personal biases and emotional connection to the communities served, resourcefulness, and commitment to achieve outcomes has guided her interaction with the participants as well as the systematic data collection process and the dissemination of the findings. Participants had no prior relationship with researchers.

Phase two

An on-line questionnaire via Survey Monkey™ (see Supplement III for sample questions) was chosen to obtain a wider perspective of the service delivery system, which was not captured within the existing qualitative data in phase one, and to generate a national perspective on wheelchair service users' experience and level of satisfaction with wheelchair and seating provision services in the Republic of Ireland.

Sample

Convenience and snowball sampling was chosen, recruiting participants via non-governmental organisations that do not directly provide wheelchair and seating services. Participants were invited as wheelchair services users, including wheelchair users and/ or their representatives over 18 years or parents of children under 18 years. The non-governmental organisation's representing a sample of wheelchair users across the life course included Multiple Sclerosis Ireland, Muscular Dystrophy Ireland, Irish Wheelchair Association, Spina Bifida Hydrocephalus Ireland and Spinal Injuries Ireland. Links to the on-line survey were posted via their social media sites (e.g. Facebook and Twitter) and sent via email. Of the possible 40,000 wheelchair users in Ireland it was anticipated that response rate of 1,000 participants could be achieved. However, given the nature of e-surveys, accessibility to gatekeeper sites and the complex characteristics of the population, a non-representative sample was expected.

Questionnaire Design

This questionnaire design was based on previous postal and on-line surveys [42, 19] and concepts from the organisational ethnographic study evaluating wheelchair and seating provision in the Republic of Ireland [9]. This comprehensive questionnaire, taking approximately fifteen minutes to complete, consisted of 41 closed questions with an opportunity to make open comments relating to the wheelchair and seating provision process from referral to follow up and management, incorporating guidance from a number of sources [19,42–45]. Survey Monkey was used for this questionnaire and is a tool commonly used to administer surveys that ensures anonymity of respondents [46,47].

Validity and Reliability

The survey was previously designed, piloted by Kane [42] and adapted by Gowran et al. [19] to ensure content and face validity by piloting the questionnaire with the target population to ensure the questions aligned with the objectives and aims of the current study.

Data Analysis

Descriptive and frequency analysis was performed on the numeric data using Statistical Package for Sciences (SPSS) version 20.0 for Windows™. Conventional content analysis [48] was performed on the qualitative data obtained from the open comments.

Ethical Considerations

Ethical approval was received from the University's Faculty Research Ethics Committee [2014_09_16_EHS]. In phase one, written informed signed consent was sought and provided by all interview participants prior to their participation in the study. Similarly, in phase two, an information sheet about the study was provided at the beginning of the e-survey. Both phases indicated the voluntary and confidential nature of the studies, outlining strict data management procedures.

Findings

Phase One

The participants (n=8) in phase one (pseudonyms are used throughout for the interviews) symbolised wheelchair users with congenital, acquired, and progressive neurological conditions (see table 1). These interviews provided the opportunity to gain an understanding of the wheelchair and seating provision process when meeting a variety of needs.

The meaning of wheelchair and seating assistive technology and the wheelchair and seating provision experience illustrates the essentiality of this technology for living and the impact the service delivery system. Four themes captured the primary position wheelchair and seating assistive technology has in the participants' lives: freedom and quality of life, embodiment, waiting times at each stage in the process, and worrying about repair services.

i) Freedom and quality of life

The importance of wheelchair and seating for daily performance was expressed by all participants in terms of “freedom”, “independence”, “quality of life” and mental health. The sense of freedom and autonomous independence associated with ‘doing everyday things’ was expressed by all with the majority (n=6) attributing this to the change from using a manual wheelchair to using a power wheelchair. Having a power wheelchair gave, as Julie stated,

“Freedom, freedom literally, seriously, yeah, after being in a manual chair like for so long, you know I was like a child, ye know with it first and then it sinks in that I’m going to be in it for a long time so it kind of, you don’t be as excited ye know. So you just carry on and make the best of it.” [Julie]

The wheelchair enabled people to get out of the house, go to work, meet friends and socialise. For Lisa (mother), having a wheelchair enabled them to function “effectively as a family”. Without the wheelchair, Jim said he “can’t move”. This was reiterated by Mark as he explained that with the wheelchair he “was able to” “participate in society”, and without his specialised wheelchair he “can’t operate”. Simon expressed that his wheelchair gave him a greater “quality of life” and “independence”, stating, [you] “have to have quality of life, it

has to come first". The wheelchair enhanced positive mental health, enabling people to "do things" as described by Philip

"...A typical day, life in a wheelchair you just do things to try and keep busy. I used to suffer depression and I'm bugged if I'm going to face that one again. ...No way! The only time I want to go to bed is with a beautiful young woman. Otherwise forget it" [Philip]

Participants described the wheelchair as being part of them, illustrating a second theme:

ii) Embodiment

Simon said "*the chair is my freedom. Freedom is me*" and he explained this in relation to the impact of his wheelchair breaking down,

"... my parents say the chair is not you, you know, when the chair breaks down it shouldn't be a big deal and it shouldn't make other people know that it's a big deal. But it is a big deal ... no matter how strong you are inside; you are going to feel down because you can't get out...you can't do your everyday things. Just simple things are affected. Ye know, you can't even, getting a drink of water is even a difficult thing." [Simon]

Mark explained that the wheelchair "*It's not like a car*" but is more a part of him, saying,

"But it's crucial, as I said, it's my legs, I can't go, I can't go. It's like once the chair stops, it's like cutting my two legs off, I can't do anything". [Mark]

Julie elaborated on how "*It's like part of my skin now*" and how amazing it was driving a power wheelchair,

"...and I'm a dab hand driving it [power chair] now, it's amazing in a way it's kind of like your senses, the way you can narrow, you know, you, how narrow or it's too narrow or whatever and it's amazing, you think you have eyes in the back of your head, but it's just your senses." [Julie]

As a parent, Lisa expressed how the wheelchair embodied the family, being "*a massive part of my [her] life...massive in our house*"

Although users expressed that the wheelchair was an embodied part, some users wanted to blend in and be 'normal' in society. Others expressed that they would rather not have to use a wheelchair. Simon described how,

"...ye know the greatest thing for me is independence to move, visiting my friends, being as 'normal' in society as 'possible', that's the biggest driving force for me, like ye know..., you don't want to be dependent on people, you want to do your everyday things, simple things." [Simon]

For Mary it was important that the chair was not "*stand outish*" almost as if she not only wanted to blend in with everybody else, but she wanted the chair to blend in as part of her, so

much so that it seemed she sometimes forgot that she uses a wheelchair. Meanwhile, Mark described his hope of “a cure”. This desire to be ‘normal’ was reiterated by Philip saying,

“I’d love to be like you. I’d love to be walking around the place. I’d love to be going out to the bar. I’d love to be talking and chatting and drinking and going out and interacting with people the way I use to be without the paraphernalia of a wheelchair in tow...is utterly crap but it’s a lot safer.” [Philip]

Julie described being in a wheelchair as “another life”, explaining that she tried to make the most of it and see the positive side, “And ye know, and I’m getting a new wheelchair!” [Julie]

Lisa shares how both she and her daughter, Alice, had to come to terms with this “evil necessity”,

“...the wheelchair, it’s not what she wants, it’s not what she likes, but she realises it’s an evil necessity ye know. I imagine that’s the way she sees it. I’m only speculating because she can’t tell me. But if I could still carry Alice, I imagine she would let me. (laugh)” [Lisa]

Despite the essentiality of the wheelchair and seating assistive technology expressed through these interviews, the wheelchair and seating provision experience appeared to obstruct the “freedom” experiences as described by wheelchair users. There are many factors that can enhance or inhibit a wheelchair users’ experience of independence, from initial appointment and assessment to the follow up services necessary when a wheelchair is damaged during daily living. Delays within wheelchair and seating provision processes affecting the pace of delivery and back-up support services were indicated by participants and can interfere with the wheelchair users’ perceived freedom and independence.

iii) Waiting times at each stage of the process

Long waiting times throughout the process appeared to be a major cause of concern and can be affected by cancellations. While cancellations did not appear too large in number, they did impact the provision of timely assessments. Once service users had appointments scheduled, some experienced barriers with transportation and/or personal assistance supports during their visit. Jim explained one of the reasons that people did not turn up for their appointments,

“Well the main thing for me is that we get confused with how much support people need, and how much they don’t need. We haven’t found that right balance.” [Jim]

This caused frustration at times as it inhibited the flow of the service. The length of time required when conducting the wheelchair and seating assessment was also highlighted as an issue. Planning and prioritising to provide services for people across their lifespan with varying needs appeared to be a cause of concern. Planning services around a child’s growth and development was highlighted by Lisa,

“the challenges they face, are big enough, why would you [leave them waiting], it’s actually double. That doesn’t have to happen,... Alice is coming out of that chair in 3 months’ time because she is going to be squashed. Have the new chair ready. Very simple! In my head it’s very simple. But actually the process is not

very simple, ye know so. Yeah, I'd love you to see her actually, love you to see her squashed into her chair." [Lisa]

In addition, the progressive and changing nature of conditions are important considerations when planning services. Mark explained the importance of planning ahead, as from his experience it could take up to two years to get a wheelchair, sharing that he was *"surprised"* when he received his new power wheelchair within seven months. The importance of providing wheelchair seating and assistive technology in a timely fashion was highlighted as Mark provided an example of the how people with muscular dystrophy's *"life span is dramatically reduced"* and that he would *"like to see people get what they deserve"*.

Waiting times causing delays between each stage of the process was highlighted during interviews as Mary pointed out,

"Yeah, it's a very long process cause well you've to go and get fitted for it and then you wait and that's grand everything's done and then you wait to hear back from the ... Health Board whether you can have it or not and they have to put the actual order in. So you could be waiting for another three months maybe if not more depending on how busy the company is..." [Mary]

Waiting for funding to be sanctioned by the Health Service Executive (HSE) to pay for technology caused delays which made life difficult. These delays impacted not only on the people waiting on the wheelchair and seating but also on their family, particularly for growing children, as Lisa expressed,

"Rotten [waiting], 'cause I feel like I'm letting her down...Like I understand that they have their processes and their procedures, but as a parent, it drives me insane, that nobody has thought that this child needs a chair, before it becomes a problem." [Lisa]

Julie explained that she was a *"patient person"* and that she now understands the saying *"patience is a virtue, ha, ha."*

"I just got on with it. You know what I mean, ... I knew my appointments and sometimes I couldn't make the appointments and then, we thought it was going to be before the Christmas [now March], and I start getting a little bit cheesed off. ... and then I just waited, I just got on with it. And just waited and ye know?"
[Julie]

iv) Worrying about repair services

Once the wheelchair and seating was provided there appeared to be an underlying fear of the wheelchair breaking down with inadequate repair services. Poor repair services impeded independent living and quality of life leaving users feeling *"scared"*, like they were *"putting your [their] life on the line"*.

Mark explained that the repair services were seen as the biggest problem of all. Simon noted how he was *"lucky"* to still live at home otherwise he'd be *"totally stuck"*. This is what he said,

“I couldn’t even get on the bus. Eh, so that was scary and em...Ye know. Wouldn’t be able to feed myself or do the toilet or get a drink of water. Ye know that’s how bad it would be you know?” [Simon]

Jim expressed feelings of being “trapped” and “very vulnerable” depending on where he broke down. Sarah too, expressed that poor repair services affected her plans when going out, worrying that she would “come back safe”. These poor repair services did not appear to be supported by any adequate loan system to provide a backup wheelchair while a chair is being repaired.

This inadequacy was further reiterated with issues relating to waste in the system, where refurbishment and reuse appeared to be ad-hoc. Lisa suggested a possible solution:

“Find a wheelchair temporarily, while we’re waiting for the new wheelchair. I think that would be good. Some parents don’t like accepting, second hand bit and bobs, but I mean, I think recycling, your wheelchairs, especially in an economic down turn surely the base of Alice’s wheelchair is standard...Just to allow them, during the transition period, between small to bigger wheelchair rather than all of those discarded wheelchairs.” [Lisa]

Phase two

Phase two provides brief descriptive statistics of the results from online survey, presenting demographics and four key aspects of the wheelchair provision: access to services, assessment and delivery, education and training skills, and follow up, repairs and maintenance. A more detailed analysis relating to specific diagnostic categories will be presented at a later date.

Demographics

The online survey was completed by 273 respondents. Of the total respondents the 85.7% had a primary diagnosis of either Spinal Cord Injury, Cerebral Palsy, or Spina Bifida (table 2).

The majority of respondents were of working age and 20.9% indicated that they were parents or carers of children with congenital conditions under the age of 14 years (see table 3).

The length of time people had been using wheelchairs ranged from less than one year to more than 20 years (see table 4) with the majority of people reliant on their wheelchair all of the time (see table 4).

Of those who participated, over one third did not feel that their wheelchair and seating system met their needs. Many respondents reported that their wheelchair and seating system did not provide adequate support, fitted incorrectly, was uncomfortable, was in need of a review or was awaiting repair. Over half of the respondents who felt that their needs were met mainly commented that their wheelchair seating and assistive technology was comfortable and provided increased mobility and independence.

Access to Services at each stage of the process

Participants could wait anywhere between one day and four years during different stages of the wheelchair seating and assistive technology service delivery process (see table 5).

Out of all respondents (n=228) just over half reported that they were satisfied, however, a fourth of the participants reported dissatisfaction, with the remaining participants undecided. Where participants had the opportunity to make open comments, some expressed satisfaction with their experience, praising the health professionals,

“Having a good OT and PT makes all the difference”

“The Occupational Therapist with responsibility for my area is very understanding...”

However, the majority criticised the service providers, in particular the HSE, which is responsible for health and personal social service provision for everyone living in Ireland with public funds. Participants expressed dissatisfaction with their experience of the whole process, describing it as an *“Utter nightmare”*, with many referencing the waiting time, stating *“I believe the process was too long particularly as I am totally reliant on a wheelchair”*. Some participants described the impact that unsatisfactory wheelchair service provision has on their lives as a human rights issue,

“The HSE has taken away power, choice and control from the very individuals that should have gained independence from these services.”

“We have a right to a chair that doesn’t make things more painful and endangers our lives further.”

Assessment & Delivery

The findings suggest that the majority of people received a comprehensive wheelchair assessment, including a physical assessment relating to comfort, movement, life style needs and measurement. However, between 10 to 15 percent of people reported that these assessment components were not addressed. In addition, of the 240 who responded, over a fifth of participants reported having no choice regarding wheelchair selection.

Once assessments had been completed, participants experienced varying delays waiting for funding, with the majority being funded by the HSE. Some respondents highlighted the need for more accountability in the current funding system that *“prevent(s) the swift availability to funds for equipment so that the lives of people with disabilities can be measly [meagrely] improved”*. Many participants commented on importance of the wheelchair, for example,

“...shouldn’t be any excuses for funding delays to provide vital equipment for people with disabilities in my opinion”

“It takes way to long for reports to be written up and supplied to the HSE. There are always issues and delay, when the chair is urgent it should be urgent”

A large range in wait times for delivery was reported by respondents, from on the day to up to 4 years. Once the wheelchair arrived the majority stated that it was correct size and adjusted correctly, however almost a fifth said that they could not do things they needed to do with their wheelchair.

Education and Training Skills

Over a third of the participants who responded to this section (n=232) received no training at all relating to transferring in and out of the wheelchair, moving about in the wheelchair, staying healthy in the wheelchair, or looking after or dismantling the wheelchair (see figure 1).

Of the participants who commented some felt that they did not need training and others felt that training was not addressed,

“I’ve been using a wheelchair all my life and could probably teach health professionals a thing or two”

“I have had no specific training I have good knowledge of bicycles, mechanics and upholstery, I have learnt wheelchair skills from other wheelchair users”

Follow up, repairs and maintenance

The majority of participants responding in this section (n= 232) stated that they were provided with follow up contact details for problems with wheelchair and seating. However, only 21 percent of respondents (n=228) received a follow up appointment within six months of receiving their wheelchair. It is unclear from the results if those follow up appointments were instigated by the participant or the service provider. Of those who received maintenance and follow-up, almost half of the respondents reported satisfaction with the services. However, only 41 percent of respondents needing repairs were satisfied with the service they received, with almost a third dissatisfied or very dissatisfied with the repair service.

Participants highlighted the impact of irregular follow up and a need for *“routine maintenance inspections and service to keep chairs in top condition and avoid injuries and stress”*. Many participants described their dissatisfaction with the long wait time for repairs, especially relating to the unavailability of ‘critical replacement parts’ and their lack of mobility while repairs were being made, stating,

“...the service team has never dealt with the particular model of wheelchair, therefore is unfamiliar with it and has no spare parts readily at hand”

“I can't use the manual chair as I can only use one hand/arm! So result- I'm back in bed until it's fixed!”

Some participants described fixing the wheelchair themselves rather than relying on a service appointment,

“We try and fix it ourselves or bring it to a bike repair shop. If [users] wheelchair is out of action for any length of time he is unable to attend or leave the house.”

“I look after the chair maintenance and repairs myself, even though I could get the HSE repair services involved.”

“we are waiting since [3 months] for it to be fixed, I asked for the parts and I will fix it myself but nothing yet”

Many described satisfactory service with caution highlighting the inconsistent and *“hit and miss”* standards of repair services received,

“The level of service by the maintenance company is patchy-I have had good and bad services”

“a broken brake handle... was dealt with very quickly but was told by others that speedy service is the exception rather than the rule”

Discussion

The overall findings of this study demonstrate the heterogeneity of people who require wheelchairs spanning all ages and various diagnoses, and highlights the complexity of appropriately meeting individual needs as well as potential challenges faced when delivering wheelchair and seating services. A combination of wheelchair, supply, environmental, personal, user-centred and organisational variables interact to affect wheelchair seating and assistive technology provision, as outlined by Kamaraj [49]. Many of these variables were accounted for from the wheelchair users’ perspective during this study and areas where service provision can improve, such as waiting times, have been identified.

The meaning of wheelchair and seating provision **was** outlined by all participants during the interviews in phase one, whereas the online survey in phase two clearly outlined lack of uniformity across the service provision process. This was evident given disparities in waiting times during each stage of the provision process, poor evidence of education and training for the wheelchair user, and little follow up after service or delivery, calling into question the value placed on providing an appropriate wheelchair and the understanding of what the wheelchair means to wheelchair users [19,50]. Participants in phase one conveyed a sense of freedom and autonomous independence in relation to their wheelchair, with the majority of them expressing this response when transitioning from using a manual to a power wheelchair. This sense of freedom can be advantageous for many as it has been well documented that powered mobility has greater benefits for people with complex seating and mobility needs [51]. This enhances the quality of life not only for users but also their families and carers, increasing overall freedoms and daily performance.

Participants in this study shared a combination of feeling insecure, vulnerable, and yet satisfied with the wheelchair and seating provision process due to the importance of having a wheelchair, **echoing findings from** Rousseau-Harrison et al. [54] in that the wheelchair was perceived as a facilitator of life habits and was a pre-requisite on Maslow's hierarchy of needs. Although participants identified stresses such as anxiety and a sense of insecurity towards being vulnerable to adverse events as well as lengthy waiting times for **follow up and support services**, the overall benefits of the wheelchair and seating provision process, such as acquiring an appropriately fitting wheelchair, appeared to outweigh these concerns [52,53]. The importance of wheelchair and seating assistive technology to enable meaningful occupations has been further highlighted by Beattie and Cornick [55] and Borg et al. [56], advocating a human rights perspective around the essentiality of a wheelchair for overall functioning and equal opportunities.

Embodiment was expressed strongly by all participants in phase one interviews. Moser [56, p. 380] identified with this theme during her case study, noting that 'the body must remain attached' to the technology in order for a wheelchair user to maintain central control of their lives. Papadimitriou [21, p. 695] described this as 're-embodiment practices', as the wheelchair becomes part of a person's being. The wheelchair also appeared to embody or enable the whole family, rather than just the individual, highlighting the importance of family and carer involvement throughout the wheelchair and seating provision process [58]. For some, the wheelchair was perceived as an "*evil necessity*", which Ripat et al. [50] reiterates by noting the levels of connection people have with their wheelchairs, sensing loss or a feeling of difference and wishing that life was different. This **mirrors the findings of Edmonds et al. [59] who found that participants mourn the loss of their mobility**. Despite these challenges, participants Julie and Philip expressed their ability to come to terms with the loss of their independent mobility by adopting a positive attitude to their new circumstances.

Along with identifying the need for a wheelchair to be an integral part of the wheelchair user, many wheelchair users also **felt** that the wheelchair could be a barrier to how they are perceived by others in the community. Zitzelsberger's [60, p. 401] findings were similar following her exploration of women with physical impairments, as they reported shifting 'in and out of subjective positions', of being visible and invisible, which she suggests shows the diversity existing within specific cultural contexts and how the body was represented and accepted on a daily basis.

The wheelchair and seating provision experiences reported by participants demonstrate how the pace and temporal quality of the service delivery has impacted their overall experiences as a wheelchair user. Bottlenecks within the system describe national wheelchair and seating provision issues, echoing De Witte et al., Kane and Gowran et al.'s conclusions [9,17,19,42]. Evidence here suggests that the entire wheelchair seating and

assistive technology provision system requires review considering the number of issues presented and the critical impact it had on the participants. Stronger system thinking is required to create market changes leading to fair access to assistive technology for all [61].

Waiting times throughout the wheelchair seating provision process appeared to be a major concern for all participants in this study. Phase one highlighted that keeping appointments and avoiding cancellations were considered to be important to avoid delays and increased waiting times as missing an appointment has repercussions within the whole system. Kylberg's [62] found that long wait times resulted from poor prioritisation of services and availability of devices, while in this study, Jim suggested that providing additional support and developing a greater understanding of wheelchair service users around the importance of the appointment would be beneficial to reduce cancellations. Phase two further supports the lack of uniformity across the board regarding waiting times for appointments, assessment, repairs, funding, and the delivery. These results support the need outlined by Durocher et al. [63] for the development of legislation that equitably offer funding and services for wheelchair seating and assistive technology that meet all individuals' needs.

Findings reiterate the negative impact of inadequate planning and prioritisation of services and supports for individuals across their life span, highlighting the importance of taking critical factors such as age and medical condition into consideration on an individual basis. Two examples provided by participants in this study include planning for growth with children and anticipating the progressive or changing nature of a person's medical condition, such as with Multiple Sclerosis. The impact that poor planning has on a child could have major consequences for their overall physiological health, posture, mobility and social development as well as their overall wellbeing and participation in life [65,66]. Farley et al. [67], also note that additional stress compounds an already challenged lifestyle, such as with children who require 24-hour care due to the presence of profound physical and sensory impairment. Participants who reported having progressive neurological conditions require their needs to be prioritised proactively because of the changing nature of these conditions. Due to the unpredictable nature and rapid deterioration noted with such conditions, regular review of the person's wheelchair and seating is indicated and requires urgent response times [68,69]. Delays in response times are also a result of waiting for wheelchair seating and assistive technology funding to be sanctioned by the HSE. Long waiting times have a negative impact on participants and their families and may also result in equipment no longer being suitable to meet the persons' needs, particularly with growing children [65,70]. Psychosocial, intrapersonal, and social-ecological factors, as well as access to resources can significantly impact assistive technology use across developmental stages and are subject to change across a person's lifetime, requiring attention to their evolution throughout the wheelchair seating and assistive technology provision process [32]. The urgent need for prioritisation of clinical research, barriers to access, social perception, and increased standards of service and policies for children using powered mobility technology from the human rights perspective has been identified [64,65].

Once the wheelchair seating and assistive technology is delivered, education and training regarding use and overall management is of paramount importance [28,71–73], yet findings from phase two highlight significant disparities regarding the type of education and training skills participants received. While it is noted that many participants have been wheelchair users for a number of years, the majority of participants completing the survey acquired the use of a wheelchair as adults.

This study echoes findings by Toro et al.'s [74], where participants voiced their fear in relation to the trustworthiness of their wheelchair, differences in repair service, and the significant adverse consequences of requiring repairs. Poor follow up, repair, and emergency services appeared to be major issues for participants with the majority of participants

receiving no follow up services within six months of receiving the wheelchair and thus contesting the World Health Organisation guidelines [28]. The HSE medical device and equipment management policy, although not specifically related to wheelchair repairs, identifies management of medical devices as a priority [75]. This is welcomed, as the inadequacies expressed here regarding this aspect of wheelchair and seating provision appears to have compounding negative consequences for the wheelchair user. Active and long term follow-up is crucial in a wheelchair seating and assistive technology provision system and allows for adjustments to improve fit and reduces accidents [73,76, 77]. **Poor follow up and support** services appear to instantly unravel all the positive achievements gained in providing wheelchair seating and assistive technology to enhance users' independence and community mobility. The evidence highlights the fragility of independence under the current system. Provision on one hand recognises the need and on the other ignores it: now you are independent, now you are not.

Considering the findings of this study, it is hardly surprising that issues regarding waste within the system arose. While there is some evidence that there have been improvements in recycling wheelchairs, there was little reported as to how adequate these systems of reuse, refurbishment and recycling of equipment were when compared to other **systems such as those in Nordic countries [78, 79, 80]**. A qualitative study, by Vincent [81] involving key stakeholders concluded that there was a need for a specific recycling policy for all types of healthcare equipment and this required cross sector collaboration. Refurbishing and recycling should be considered within the wheelchair seating and assistive technology provision process to develop a sustainable provision strategy [82].

Study strengths and limitations

Phase one and phase two had a number of limitations. Limitations of phase one include the limited number of participants who shared their experiences through interviews. A more detailed qualitative study on the experiences participants represented here across the life course with varying diagnoses would have enhanced these findings further. Phase two quantitative results enhance the potential impact on a greater number of people and strengthens this study by incorporating participants experiences within the larger ethnographic study (See table 1) [9]. Findings are supported by evidence from a previous survey carried out by Gowran et al. [19] and Kane [42] to evaluate wheelchair users' satisfaction and experience of wheelchair and seating provision in the Republic of Ireland.

Implication for wheelchair and seating provision practice

These findings challenge wheelchair and seating provision practice in this field with the reporting of the fragility of engagement for this participant group. Key professions involved in the assessment and provision of wheelchair and seating assistive technology have a responsibility to highlight the issues expressed by participants here. MacLachlan [61] highlights the importance of cooperative planning that incorporates the voices of various stakeholders and the intersections between individual, service provider, and international system levels. The professions involved in service provision must review their practice and systems from a political perspective. Such advocacy is essential to develop appropriate wheelchair and seating provision services, which are accessible, timely and provides adequate **follow up and support services.**

A national review of wheelchair and seating provision service is called for to assess the entire process as outlined by the World Health Organisation [28], giving consideration to access to services, assessment and delivery, follow up and management and education and training [9]. Developing a sustainable wheelchair and seating provision system which blends into the background as a prerequisite to peoples' lives, becoming part of the natural way of

things is required [9,32]. This approach supports the World Health Organisation/ World Bank Report on Disability advocating for a focus on universal design that enables social participation and independence for all [26]. Policies that increase access to assistive technology for everyone are stepping stones towards achieving international strategies such as Sustainable Development Goals, namely goal 3, to promote wellbeing and ensure healthy lives for all [27,83]. This research aligns with the 2018 Wheelchair Stakeholders' Meeting priority actions of building awareness and collecting data on unmet needs, product and service quality and impact of appropriate wheelchair provision from the wheelchair seating and assistive technology service users' perspectives within an Irish context [30]. Perhaps Ireland could be included in the 10 countries to realise United States Agency for International Development's goal to have a range of appropriate wheelchairs and strengthened adequately sourced, evidence-based, policy supported wheelchair services by 2023 [30].

Conclusion

The overall service provision system has impacts on wheelchair users' daily balance and temporal order, making it difficult for individuals to organise their lives [83]. These results outline a better understanding of the impact of wheelchair provision from the service users' perspective, which is a key consideration in the planning of wheelchair seating and assistive technology provision services [5,32]. These findings appear to contradict the ideology of human rights and equality, as wheelchair users, despite their initial or perceived independence, were plummeted in an instant to being dependent when faced with barriers during the wheelchair and seating provision process. These results support findings in the literature, highlighting the lack of uniformity across wheelchair seating and assistive technology service delivery processes, suggesting this state is compounded by lack of specific government policy, regulation or guidelines [73,85]. Therefore, given the distinct lack of specific policy available in the Irish context, the importance of wheelchair and seating provision appears to be misunderstood and deserves further investigation involving the Irish people [9]. This would provide the opportunity for a greater understanding among the people, thus reducing stigma attached to wheelchair use avoiding outcomes such as non-participation and assistive technology abandonment.

Appropriate wheelchair and seating provision is a human rights issue and is a pre-requisite for survival and personal mobility. This research gives voice to some of the issues faced by people who need to use wheelchair and seating assistive technology to afford them the choice of participation in life on an equal basis with others. **While this study was conducted within the Irish context, findings are likely relevant on an international level as wheelchair users in many other countries encounter similar issues.** From a human rights perspective, it is a right to access adequate assistive technology that meets individuals' personal health and well-being needs to enable them to participate in society over their lifetime [86]. Injustice will prevail if wheelchair and seating assistive technology professionals do not give political voice to the issues raised here in order to avoid jeopardizing individuals and their families' health, wellbeing and opportunity to participate and potential contribute to community and society.

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Table 1. Wheelchair and seating service user participants interviewed (n=8)

Pseudonyms	Wheelchair Service Users – includes one parent representative	Type of wheelchair & seating
Lisa	Mother with one child with Cerebral Palsy (CP)	Transit wheelchair (n=1)
Jim	Adult /CP	Special Seating Systems (n=7) Off the shelf pressure relieving cushion (n=1)
Sarah	Adult /CP and AAC user	
Philip	Adult with Multiple Sclerosis (MS)	
Mary	Adult with Spinal trauma	
Simon	Adult with Paralysis	
Julie	Adult with traumatic spinal cord injury	
Mark	Adult with Muscular Dystrophy	

Table 2. Primary diagnosis of wheelchair and seating service user participants surveyed (n=272)

Primary Diagnosis	Number	Percent
Spinal Cord Injury	117	43.0
Other	39	14.3
Cerebral Palsy	34	12.5
Spina Bifida	30	11.0
Muscular Dystrophy	28	10.3
Multiple Sclerosis	17	6.3
Acquired Brain Injury	4	1.5
Stroke	3	1.1
Missing	1	0.4

Table 3. Age of wheelchair and seating user participants surveyed (n=273)

Respondent	Age of Wheelchair and Seating User	Number	Percent	Total Percent
Parent, carer of child, or child WSAT user	5-14	57	20.9	20.9 (n=57)
	Working Age	15-24	19	7.0
	25-34	47	17.2	
	35-44	37	13.6	
	45-54	42	15.4	
	55-64	40	14.7	
Retirement Age	65-74	24	8.8	11.4 (n=31)
	75+	7	2.6	

Table 4. Length and time of wheelchair use (n=273)

Length of time as a Wheelchair user	Number	Percent	Average time use in wheelchair	Number	Percent
Less than 1 year	15	5.5	All of the time	218	79.9
1-5 years	65	23.8	Once a week	11	4.0
5-10 years	62	22.7	2-3 times/week	10	3.7
10-20 years	56	20.5	4-6 times/week	8	2.9
20+ years	75	27.5	1-2 hours/day	2	0.7
			3-4 hours/day	8	2.9
			5-6 hours/day	5	1.8
			6+ hours/day	11	4.0

Table 5. Wait times across the WSAT service delivery process

Wait time for appointment to be assessed (n=259)		
	Number	Percent
Less than 2 weeks	41	15.8
2-4 weeks	38	14.7
1-2 months	50	19.3
2-3 months	45	17.4
3+ months	38	14.7
3-6 months	17	6.6
6-12 months	11	4.2
1-2 years	10	3.9
Unsure	9	3.5
Missing	14	5.1
Wait time for funding approval (n=240)		
	Number	Percent
Less than 2 weeks	15	6.3
2-4 weeks	22	9.2
1-2 months	29	12.1
2-3 months	30	12.5
More than 3 months	13	5.4
2-3 months	18	7.5
6-12 months	18	7.5
>1 year	12	5.0
4 years	1	0.4
Unsure	48	20.0
N/A	34	14.2
Missing	33	12.1
Wait time for wheelchair and seating delivery (n=232)		
	Number	Percent
On the day	6	2.6
Less than 1 week	5	2.2
1-4 weeks	49	21.1
1-2 months	38	16.4
2-3 months	49	21.1
3-6 months	53	22.8
6-12 months	14	6.0
1-2 years	9	3.9
2-4 years	2	0.9
Unsure	7	3.0
Missing	41	15.0

Title: Wheelchair and Seating Provision a Gateway to Freedom

Implications for rehabilitation:

- 1) Wheelchair and seating provision as a basic human right is misunderstood
- 2) Appropriate wheelchair and seating provision should be provided to meet this primary need as a pre-requisite for survival

Every aspect of wheelchair and seating provision processes impacts on occupational performance, equality of opportunity and community mobility. Wheelchair and Seating Assistive Technology professionals and providers have a responsibility to review their practice and service provision systems.