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for young
wheelchair
users



Mobility Matters

**A Youth Perspective on
NHS Wheelchair Services**





We are the Youth Board, a group of young wheelchair users representing children and young people across the UK. Through this work, we set out to understand two key questions:

1. Do children and young people feel they are receiving the right wheelchair for their needs?

2. How does having the right equipment affect independence, confidence, and daily life?

Our report highlights inconsistencies in the provision and approach of NHS Wheelchair Services across the UK. We are calling on policy makers to engage with us and improve opportunities for all young wheelchair users.

Whizz Kidz Youth Board



Mobility Matters: A Youth Perspective on NHS Wheelchair Services brings together the voices of more than 200 young people and their families to shine a light on their experiences of NHS Wheelchair Services. Their stories reveal consistent and concerning themes: long waiting times, equipment that fails to meet individual needs, and the frustration of not feeling heard or understood by the systems designed to support them.

Whizz Kidz is immensely proud of the Youth Board for elevating these issues and transforming lived experience into momentum for change. Their work underscores the urgency of ensuring that every young wheelchair user receives equipment that supports their independence, comfort, and long-term wellbeing.

We are calling on policy makers to review how NHS Wheelchair Services are commissioned and to reassess the criteria used to determine what equipment is provided. Crucially, we believe that children and young people must be active partners in decision-making - empowered to choose the wheelchair that best fits their needs.



Sarah Pugh, Chief Executive



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Executive summary

Each NHS Wheelchair Service is run by the Integrated Care Board (ICB) for that local area. Research has revealed that there are significant differences in how services operate. Therefore, there are equally significant differences in the experience young wheelchair users, and their families, have in accessing services. Since 2010, the NHS has released several iterations of guidance and frameworks outlining how NHS Wheelchair Services aim to deliver their services. Generally, focus is placed on providing a holistic, person-centred approach which promotes independence and individual goals and lifestyles.

A survey of over 200 young wheelchair users and their families found:

- A third (**32%**) of respondents said that they felt colleagues at the NHS Wheelchair Clinic **did not understand their needs** and did not work with them at all.
- More than three quarters (**77%**) of young wheelchair users were **not offered a choice of any kind** in the make or model of equipment they received from the NHS.
- **53%** of young wheelchair users said their wheelchair was **poor or very poor at meeting their needs** across all areas the survey asked about.
- **62%** said they were **not able to customise their wheelchair** in any way.
- There was a strong correlation between feeling needs had been understood, with the Clinician working with young people, and receiving a wheelchair that scored positively for meeting needs.

The analysis of survey responses revealed that, whilst there are pockets of good practice where NHS colleagues were doing the best they could with the resources available, young wheelchair users found their NHS equipment to be falling short. Generally, young people did not feel their equipment was suitable. None of the seven aspects on which young people and their families were asked to score how well their wheelchair met their needs saw a standout positive response. In all cases, less than half of respondents felt positively about their wheelchair, with the highest percentage of positive sentiment reaching only 45%. Young wheelchair users repeatedly shared they wanted more choice and greater involvement in the process and for their needs to be better understood. Despite this, there were examples of success, and these largely occurred when young people reported their needs being understood and clinicians working with them.

This report has found that much of the theoretical guidance that should underpin how NHS Wheelchair Services are run aligns well with what young wheelchair users and their families would like to see. However, there remains a resounding gap between the issued guidance and the reality of how NHS Wheelchair Services operate. Many of the shortcomings that families shared in their survey responses mirror those that have been raised in the past. The long-standing critiques indicate that, despite the changes made to guidance and delivery of NHS Wheelchair Services over the past 15 years, little impact has been felt by young wheelchair users.

Introduction

The Youth Board are a group of young wheelchair users, proud to each represent a different area of the UK. They meet several times a year, making sure their voices, and young wheelchair users more generally, are at the heart of every decision Whizz Kidz makes.

It is estimated that there are around 75,000 young wheelchair users in the UK. There are a variety of reasons and conditions that could mean a young person is in need of a wheelchair to get around. Each young person is unique and will have their own personal needs. As a result, the type of wheelchair they should receive will vary from one individual to another. The right wheelchair can open the world to young wheelchair users, enabling them to be independent and confident, and take on opportunities that interest them.

The Youth Board have raised the issue of suitability of the equipment provided to young wheelchair users by National Health Service (NHS) Wheelchair Services. From their own personal experiences, they have reflected on the vast difference in provision across different areas of the country. Anecdotally, young wheelchair users and their families have often told Whizz Kidz that the equipment they receive from NHS Wheelchair Services is not always suitable. We have also witnessed an increase in applications to our wheelchair and equipment service, with an average of 25% more applications each year. The high level of demand in 2024-2025 lead to the unprecedented decision to temporarily close our equipment waiting list in February 2025.

This research report seeks to understand whether the equipment provided to young wheelchair users aged 0-25 years by the NHS is suitable. It will review the current guidance and operating model of NHS Wheelchair Services and the importance of the suitability of mobility equipment, before providing an analysis of over 200 survey responses from young wheelchair users and their families living across the UK.

Research

According to NHS data¹, in March 2025 there were more than 630,000 wheelchair users currently registered with NHS England Wheelchair Services, with this figure split across 560,000 adults and 70,600 children (under 18s). In Wales, there are approximately 70,000 wheelchair users accessing NHS Wheelchair Services² whilst in Scotland, as of 2024, there were 124,000 wheelchairs on issue³. In Northern Ireland, just over 28,000 residents reported using a wheelchair in the 2021 Census⁴.

NHS Wheelchair Services

In England, NHS Wheelchair Services are delivered by Integrated Care Boards (ICBs) - the ICB for a given area is therefore responsible for the commissioning of NHS Wheelchair Services within their region based upon the needs of the local population. Whilst the NHS has developed policy guidance and legislation to support ICBs, in the current system there is no individual responsible for national oversight of NHS Wheelchair Services. As a result, the services offered vary considerably across the UK. Some are delivered entirely in house by the NHS whilst others are contracted out privately, some bundle wheelchair services in with other services, such as community or static seating services, some are delivered in hospitals and others within the local community⁵. There are differences in the eligibility criteria adopted by each service, with different thresholds and approaches to prescribing equipment, and there are discrepancies in the types, models and brands of equipment offered⁶.

There are three main delivery models for NHS Wheelchair Services; some are provided entirely by the NHS, some are contracted to a private provider, and some use a mixture of both for different elements of the service⁷. There has been a gradual uptick in competitive tendering within the NHS throughout the 2010s and into the 2020s, and the impact of this has been felt by Wheelchair Services⁸. There is increasing pressure for services to deliver value for money and better outcomes, all within shorter waiting times. This has led to several changes, notably the standardisation of equipment to save on costs which has limited choice and the ability of clinicians to prescribe the most suitable equipment for a person's needs⁹.

There is no children's or paediatric service within NHS Wheelchair Services. Children and young people, which the NHS categorises as those up to the age of 18, are seen by the same clinicians and engineers, are assessed against the same criteria, and prescribed equipment from the same matrix as adults and older people. Current guidance in England dictates that children under three years of age should be given either a standard buggy or a buggy that offers postural support – not a wheelchair¹⁰. The quarterly NHS wheelchair collection data shows that since 2019, one in five children are consistently waiting over 18 weeks to receive their wheelchair¹¹. This figure increases for children with more complex needs; in 2023-2024, 29% of children assessed as having a specialist need waited over 18 weeks. This is despite the NHS England Model Service Specification

requiring services to have developed improvement plans by 2019 to “ensure all children who require a wheelchair will get one within 18 weeks”¹².

Guidance

There are a significant number of resources and guidance documents that underpin how the NHS aims to deliver their services, covering everything from referral to assessment to the provision of equipment. The guidance has changed over time in response to issues and concerns that have been identified. The table below outlines just some of the recent research, guidance, service specifications and frameworks that govern NHS Wheelchair Services across the UK.

Guidance and research	Summary
Wheelchair and Seating Services Quality Improvement Framework (2011) NHS Scotland	NHS Scotland developed quality standards in partnership with clinical, user, carer and third sector parties. These standards underpin the framework to create ambitions for a person-centred, effective and safe service that respects individual needs and values, provides appropriate and timely support, and prevents avoidable injury or harm.
Right Chair, Right Time, Right Now (2014) NHS England Improving Quality	The evidence review found that assessment lacked a holistic approach, criteria was too strict, and wheelchairs did not always meet the needs of their user. The NHS committed to improving wheelchair services to make them more effective, efficient and personalised.
Model Service Specification for Wheelchair and Posture Services (2017) NHS England	The non-mandatory guidance highlighted ways for NHS Wheelchair Services to improve and become more person-centred. It recommended wheelchair users have greater control and choice over their wheelchair, with personal goals and lifestyle being considered. It made specific reference to ensuring a wheelchair user is as independently mobile as possible and their social, educational and employment needs are taken into account.
Personal Wheelchair Budget (2019) NHS England	The Personal Wheelchair Budget (PWB) meant that anyone eligible to access NHS Wheelchair Services could choose to either accept the wheelchair they were prescribed at clinic or receive a PWB for the same cost. The PWB was designed to support an individual's choice, whether NHS or private, with wheelchair users able to contribute their own money to receive more appropriate equipment.

Guidance and research	Summary
Posture and Mobility Services for Children, Young People and Adults Service Specification (2024) NHS Wales	The specification outlines how NHS commissioned Wheelchair Services in Wales should operate. It references the importance of accessing the right equipment and support in a timely manner, as well as the consequences of receiving the wrong wheelchair. The service aims to promote independence and quality of life.
Wheelchair Quality Framework (2025) NHS England	The framework, which was co-produced with organisations and charities who represent wheelchair users, builds upon the model service specification, recognising the inconsistencies in the provision of equipment and the importance of ensuring services are equitable. It outlines core principles to support providers to deliver a high-quality service.

The guidance introduced over the past 15 years shows the direction NHS Wheelchair Services is looking towards, with some consistent themes across the different frameworks and specifications. The guidance indicates that services should aspire to be person-centred and take a holistic approach, to respect individual needs and consider a person's lifestyle and goals when prescribing wheelchairs, and to offer control, choice and promote independence to wheelchair users.

This reflects a wider cultural shift in healthcare. The development of the social model of disability and its endorsement by the Government Equalities Office in 2014 changed the way disability is thought about and how services interact with disabled people¹³. The social model recognises that barriers such as the physical environment, people's attitudes, and the way institutions operate make life harder for disabled people¹⁴. By removing these barriers, disabled people can have more independence, autonomy and control. In the modern era, greater emphasis has been placed on living well with disabilities, human rights, and ability and engagement. The ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2008¹⁵, followed by the enactment of the Equality Act 2010¹⁶, placed rights at the forefront and promoted equality and non-discrimination across the services including healthcare.

It is essential to set NHS Wheelchair Services within their wider context. The NHS, as a whole, is under intense pressure; the *Fit for the Future* report described the NHS as standing at a historic crossroad¹⁷ and the Independent Investigation conducted by Lord Darzi found that NHS was in a critical condition¹⁸. The wider landscape of the NHS will undoubtedly impact on NHS Wheelchair Services and their delivery.

The importance of suitable equipment

The significance of having the right mobility equipment that suits the needs and lifestyle of an individual cannot be overstated. The right wheelchair can offer independence, freedom and choice to young people across all aspects of their lives; from everyday activities like getting up and getting dressed in the morning to the important life opportunities like school, college, university, and work. With the right equipment, young people can lead the lives they choose and work towards their aspirations, however big or small.

The importance of the right equipment can be most clearly demonstrated by looking at the consequences of getting it wrong. First and foremost, the wrong wheelchair can have serious impacts on a person's health, putting them at risk of secondary health issues, experiencing pain and discomfort, developing wheelchair-related injuries, and overall worsening long-term health outcomes. In addition to health implications, the wrong equipment can also limit a person's ability to take part in society through education, work, social and leisure opportunities. It is well established that children and young people with special educational needs and disabilities have much higher absence rates from school than their non-disabled peers¹⁹ – having unsuitable equipment must not be another barrier to accessing education. It is perhaps then unsurprising that the wrong wheelchair can also severely impact on a wheelchair users' mental wellbeing too²⁰.

Whilst having the right equipment is imperative for any wheelchair user, regardless of age, the importance is arguably heightened for young wheelchair users. Children and young people are not adults in miniature – their anatomy, physiology, pathology and cognitive development undergo significant change and are distinctly different to that of an adult²¹. Changes to lifestyle, living circumstances, and access needs happen more rapidly in youth than any other time. Childhood, particularly the early years, are pivotal to development²² and self-directed, independent mobility has been found to benefit a child's development significantly²³.

Survey and results

About the survey

The NHS Wheelchair Services Experiences survey was youth led in design, with the Whizz Kidz Youth Board deciding on the themes and question topics. The survey consisted of four sections – demographic information, experience at NHS Wheelchair Services, experience in daily life, and final questions.

The survey was circulated through Whizz Kidz networks, partner networks, social media channels and beyond in order to reach as many young wheelchair users as possible.

About the respondents

In total, 203 respondents answered the survey to share their experiences of accessing NHS Wheelchair Services. 17% of those who completed the survey were young wheelchair users themselves, and 83% were parent/carers of young wheelchair users. Some of the key characteristics of the cohort include:

- **Location:** 86% of respondents lived in England. The remaining 14% lived across Scotland (9%), Wales (4%) and Northern Ireland (1%).
- **Age:** A third (34%) of young wheelchair users represented in the survey data were of secondary school age, between 11 and 16 years old. Primary school age was the next largest group, with 28% of respondents aged six to 10 years. The remainder was split by 19% young adults aged 19-25 years, 12% early years aged five or under, and 7% sixth form/college age at 17-18 years.
- **Wheelchair use:** Two thirds (66%) were full time wheelchair users whilst 34% were not.
- **First Wheelchair Service interaction:** The vast majority (70%) of respondents accessed NHS Wheelchair Services for the first time when they were aged five or under and a further 15% were aged between six and 10 years. The remaining 15% all accessed services for the first time aged between 11 and 25 years.
- **Most recent Wheelchair Service interaction:** 68% of young wheelchair users to respond to the survey said their most recent interaction was in 2025, and 19% said it was in 2024. The remaining 13% had last accessed services between 2016 and 2023.
- **Type of wheelchair:** 78% of young people had been provided with a manual wheelchair at their most recent NHS clinic whereas 11% were provided with a powered wheelchair. 2% were unsure and 9% had never been provided with anything from NHS Wheelchair Services. For more information about the types of wheelchairs the NHS can offer, see appendix 1.
- **Model of wheelchair:** 38% of the young wheelchair users who were able to share what kind of wheelchair they received were provided with a Sunrise Medical model (Argon, Simba, Life, Salsa, etc). A further 32% were provided with an Invacare model (Action, Kushall, Rea Azalea, TDX2, etc).

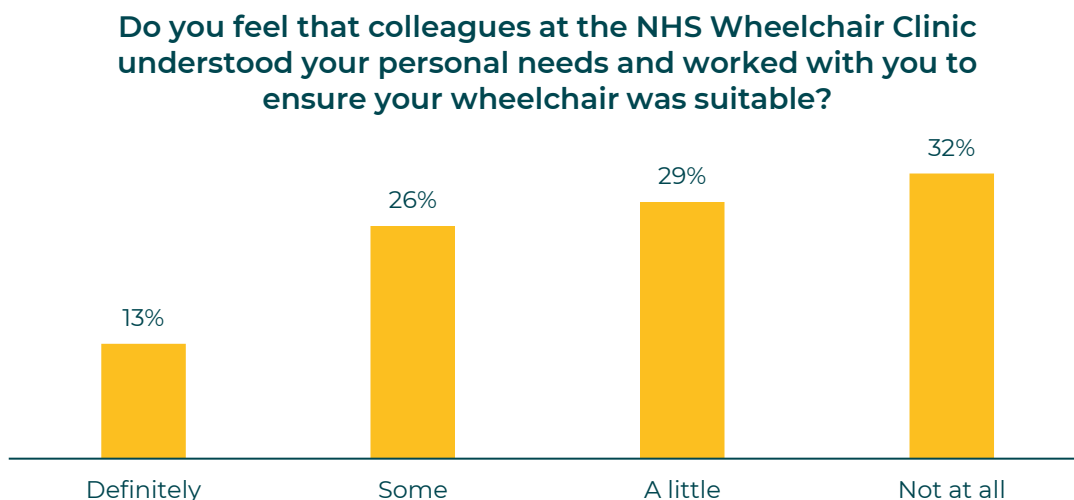
Experience at NHS Wheelchair Services

The first section of the survey asked questions about young people's experience at their NHS Wheelchair Service during their clinic appointment, assessment and handover.

A third (32%) of respondents said that they felt colleagues at the NHS Wheelchair Clinic did not understand their needs and did not work with them at all. These respondents were asked what could have been better. Their responses revolved around several themes, the main three being: the equipment received or offered was unsuitable, the young person and their family were not given enough involvement in the process, and there was an overall lack of choice. This is clear from the comments provided to this question.

- *"Listen to my perspective as the person using the wheelchair. Not belittle my suggestions and understand the impact an incorrectly set up / fitted wheelchair has on my life."*
- *"Refused to acknowledge the needs of the child, stated that development and independence wasn't important, it was only to get them from A to B."*
- *"There is no choice, the chair is basic and poor quality, it provides some independence but is based on cost."*
- *"They need better understanding of active wheelchair users, and the importance of the wheelchair being correct for our needs. I was repeatedly told I was being 'fussy' or 'too particular' when I asked for certain features of the chair to meet my needs. I was told that I could not have a fixed frame chair, even though this would best meet my needs as an active chair user, as I was not paralysed, and was not a Paralympian! They lacked understanding of the importance of postural support, telling me I could not have a hard contoured (Jay type) backrest as this was not needed. They did not ask about how my condition affected my mobility or what I needed from my wheelchair, the only decision I made was the colour!!!"*

In addition to the three main themes listed above, there were frequent comments around clinicians lacking knowledge of certain conditions, the process taking a long time, and too great a focus being placed upon cost saving.



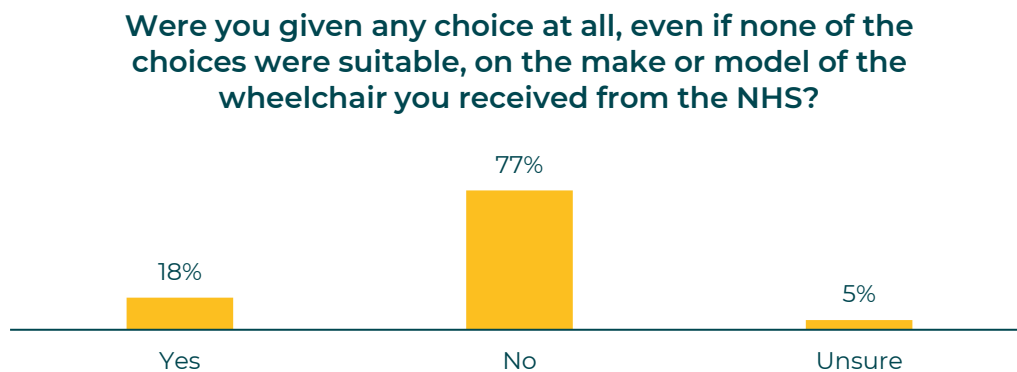
Despite the negative experiences expressed, two thirds of respondents felt their needs were understood to some extent and NHS colleagues worked with them to some degree – 12% said colleagues definitely understood their needs and worked with them, whilst 26% said they understood some and 29% said a little. Respondents were asked how NHS colleagues worked with them and the most prominent theme was ensuring equipment was a good fit and even working to adapt wheelchairs where needed to fit the young person’s needs best. Young people and their families also said that they felt listened to and that NHS colleagues were informative and helpful.

- *“My son didn’t need to leave his disability buggy to get measured as they knew this could be distressing. Also gave me options on how I’d like the chair, things like is it better to get cushions on the sides or adapt the chair for a snug fit etc.”*
- *“Listened to us and our OT about specialist seating needed to support them as they were the first children with their type of dystrophy they’d dealt with. First to receive v-trak seating but led the way for others as there is now a monthly clinic with this seating provider as it’s offered to many other osteitis.”*
- *“The OT I spoke to understood my condition but had little power with what she could order for me.”*
- *“They listened to my parents and understood what we wanted to be able to do with my chair. E.g. transfer my off-road wheels from my old chair over to the new one.”*

Choice and involvement

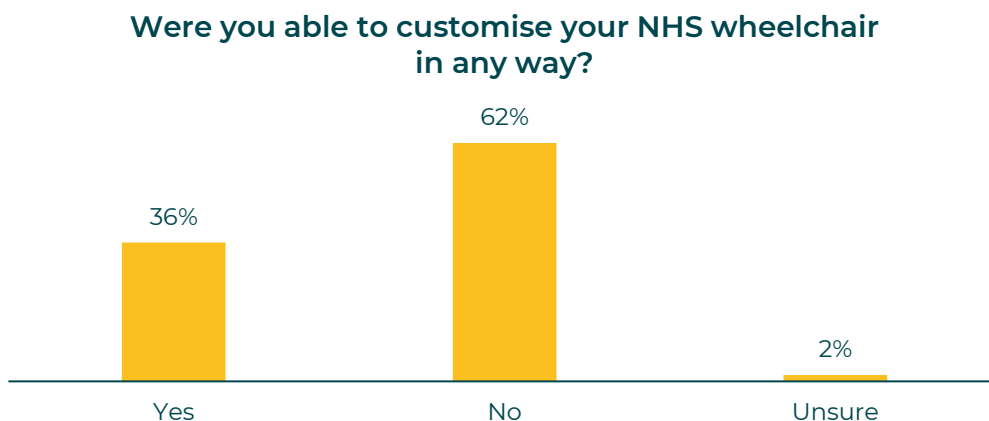
Generally, the results showed that young wheelchair users and their families had limited involvement in the assessment process and were often not offered many choices or opportunities to make decisions. The lack of involvement and choices crosscut several areas including selecting a model or make of wheelchair, the assessment process itself, the decision to utilise a PWB, and customisation

More than three quarters (77%) of young wheelchair users were not offered a choice of any kind in the make or model of equipment they received from the NHS.



The survey asked about customisation; young wheelchair users and their families were asked if they were able to customise their NHS wheelchair in any way, for example by

choosing their own brakes, tyres or colour. Just over a third of respondents said they were able to customise their wheelchair whilst 62% said they were not.

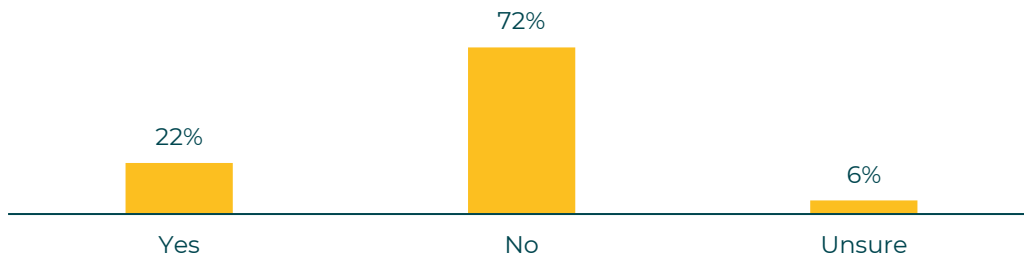


Another choice that can be offered to young wheelchair users is the choice between accepting the equipment the NHS can provide or opting to use a PWB instead. There are three main options for providing a PWB: A Notional PWB, a Notional PWB with contribution, and a Third Party PWB^{24,25}:

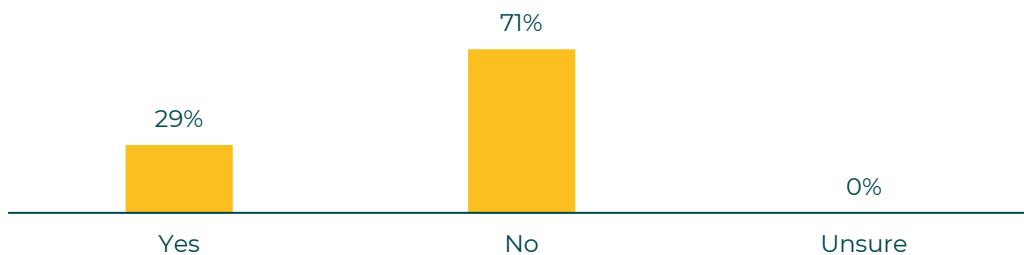
- 1. A notional Personal Wheelchair Budget:** A wheelchair is provided to the user at no cost to them. The wheelchair remains the property of the NHS and is therefore repaired and maintained by the NHS.
- 2. A notional Personal Wheelchair Budget with contribution:** This is the same as the option above, but the wheelchair user contributes their own money to upgrade the wheelchair or add extra features beyond what the NHS would have prescribed. The wheelchair is still property of the NHS.
- 3. A third party Personal Wheelchair Budget:** This involves choosing to use the PWB outside of the NHS by purchasing a wheelchair from a private retailer or manufacturer. The NHS offers a PWB worth the value of the wheelchair they would have provided the user with. As the NHS purchases wheelchairs in bulk, they frequently have contracts with manufacturers for lower prices – this means the monetary amount received could be lower than the retail value²⁶. The NHS Clinician will need to agree that the wheelchair chosen meets the user’s needs and the user will own the equipment and therefore be responsible for repairs and maintenance themselves. If the PWB does not cover the entire cost of the wheelchair, the user will need to contribute their own money to make up the difference.

Across all three options, there is no standardised amount a wheelchair user will receive. It will vary from service to service depending on their equipment matrix and their contracts with manufacturers that dictate the cost of equipment. Each ICB has developed their own local process to calculate the amount for a PWB²⁷.

Were you given the option of the Personal Wheelchair Budget?



If you were given the option, did you utilise a Personal Wheelchair Budget?



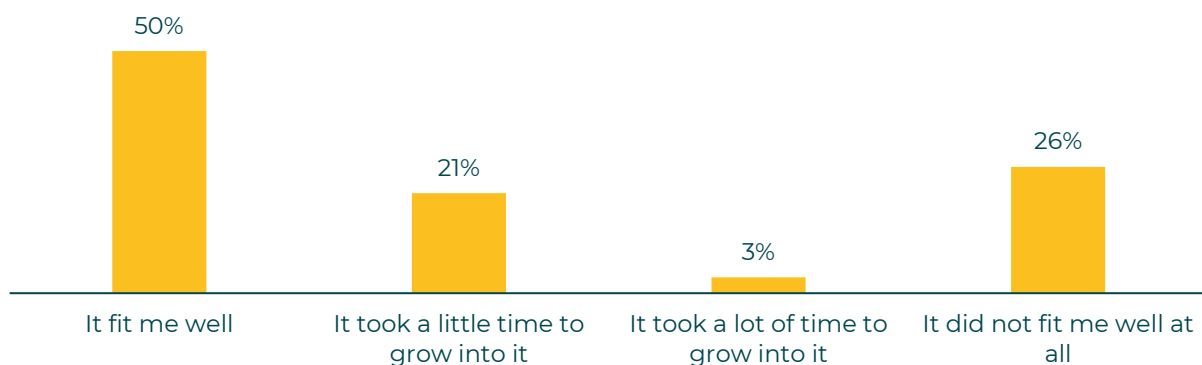
Just 22% of young wheelchair users said they were given the option of a PWB. Of that 22%, just under a third (29%) opted to utilise the PWB.

Daily life

In contrast to the first section of the survey, the daily life section asked respondents to consider how their NHS wheelchair met their needs across different aspects of their day-to-day life.

Half (50%) of all young wheelchair users that responded to the survey said their NHS wheelchair fit them well when they received it. Given that young people have growing, changing bodies, it is an important balance ensuring their wheelchair fits correctly, particularly when measurement can change between the point of assessment and the handover. Conversely, 26% said that their wheelchair did not fit them well at all.

When you received your wheelchair, did it fit you well or did you have to grow into it?



Young people were asked to consider how well their wheelchair meets their different needs:

- **Medical needs:** Does it support your condition and its management? Does it improve or sustain your health?
- **Functional needs:** Are you able to easily transfer to and from your wheelchair? Can you dress, shower, toilet, and get around all areas of your home?
- **Physical and postural needs:** Is it comfortable? Does it meet your postural requirements with the right cushion, seat belt or backrest?
- **Educational needs:** Does it enable you to access school, sixth form, college or university in the ways you would like?
- **Employment needs:** Does it enable you to access employment or volunteering opportunities in the ways you could like?
- **Social needs:** Does it enable you to spend time with friends? Can you go to the park, the cinema, the gym, your local shopping centre or do whatever else you like to do?
- **Family needs:** Does it work well for the whole family? Does it fit in the car? Does it enable you to go out for days out all together?

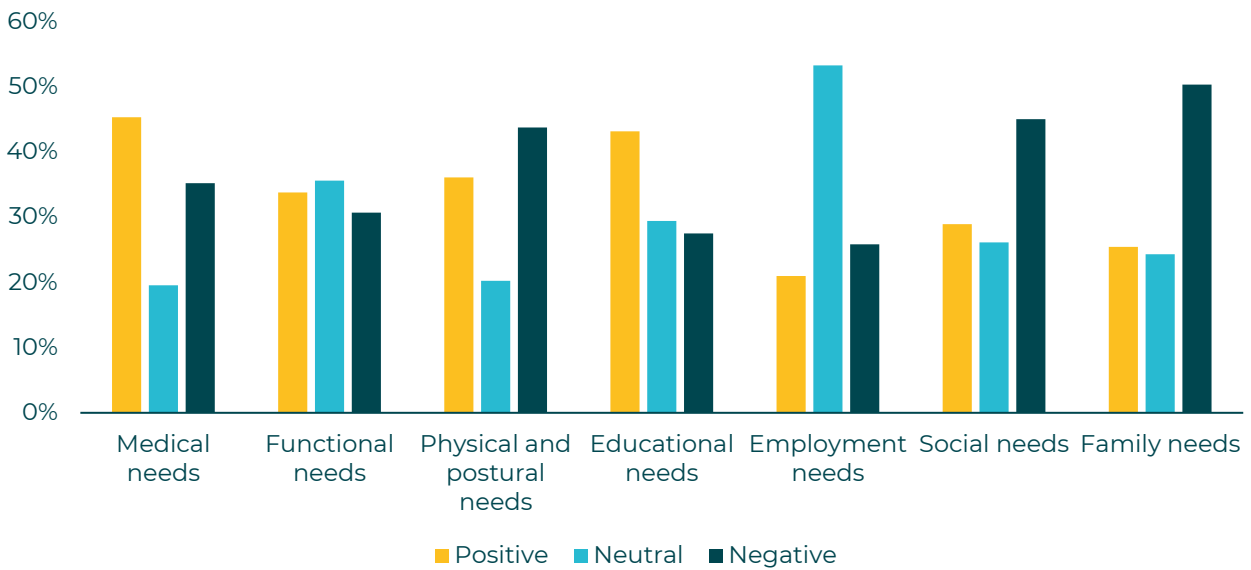
Respondents were able to rate these areas as either excellent, good, neutral, poor, very poor or as not applicable. For the purpose of analysis, those responses that were non-applicable have been omitted and responses of excellent or good have been grouped as 'positive response' and those that were poor or very poor have been grouped as 'negative response'.

The areas in which young people scored their NHS wheelchair most positively were medical needs and educational needs. Functional needs also leaned slightly more positive. That said, it is important to note that in all cases positive scores were given by less than half of all respondents. On the other hand, many people scored their NHS more negatively for meeting their employment needs, family needs, social needs and physical and postural needs.

Needs	Positive response	Negative responses
Medical needs	45%	35%
Functional needs	34%	31%
Physical and postural needs	36%	44%
Educational needs	43%	28%
Employment needs	21%	26%
Social needs	29%	45%
Family needs	25%	50%

By collating all the seven areas of need and their scores, it was found that 53% of young people said their wheelchair was poor or very poor.

Please score how well your wheelchair meets your needs in the following aspects

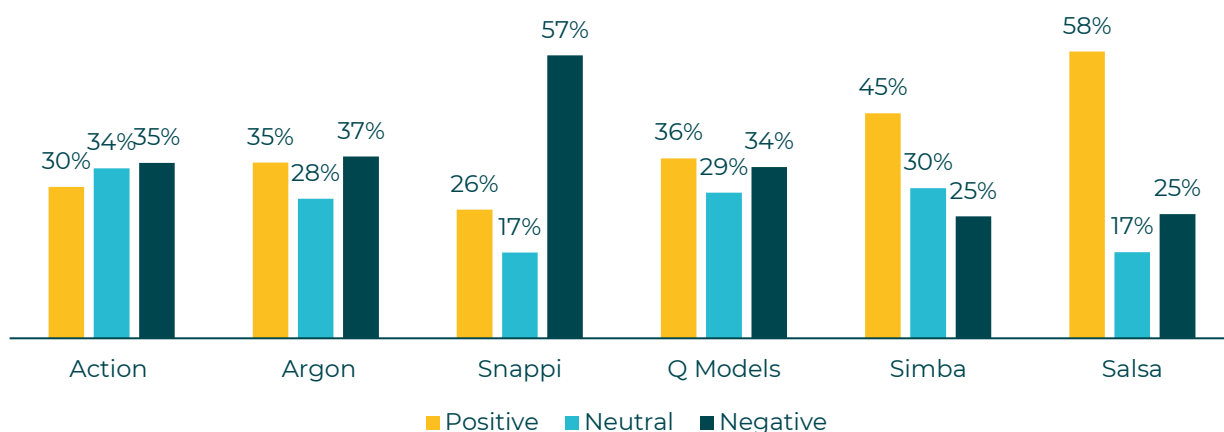


In the demographics section, respondents were asked to provide the model of wheelchair they received from the NHS if they could recall. The most common types of wheelchairs issued are shown in the following table. For more information about these models, see Appendix two.

Model of wheelchair	Percentage of responses
Invacare Action Models	26%
Sunrise Medical Argon Models	11%
Tendercare Snappi Buggy	8%
Sunrise Medical Q Models	7%
Sunrise Medical Simba Models	7%
Sunrise Medical Salsa Models	6%
Various Other Models	<5% each
Unknown	13%

The responses of those who provided this information were then cross referenced with the scores they provided above to see how different models scored when it came to meeting young people’s needs. For each model, the positive, negative and neutral scores were counted across all seven categories of needs.

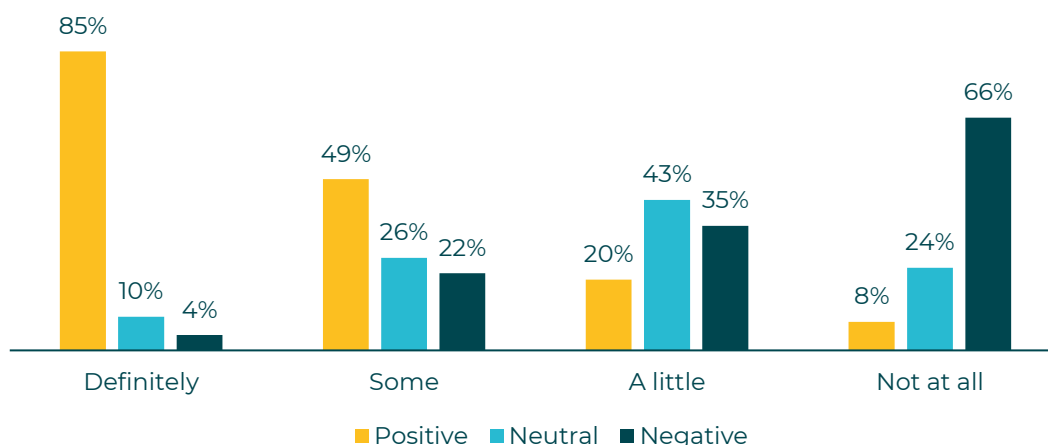
Needs met by model of wheelchair



Sunrise Medical Salsa models received the most positive responses on meeting the needs of young wheelchair users; 58% of young wheelchair users said their Q model wheelchair was excellent or good when it came to meeting their needs, and 17% scored it neutrally. Only 25% of responses were negative (poor or very poor). Sunrise Medical Simba models also performed well with, with 45% giving a positive score and a further 30% scoring the models neutral. Sunrise Medical Q models received a similar proportion of positive (36%) and negative (34%) feedback. The remaining three models all received more negative responses than positive. This was particularly evident for Tendercare Snappi buggy's, receiving 57% negative scores in contrast to just 26% positive.

Additionally, the scores provided on meeting needs were also compared to the responses young people gave to the question: *Do you feel that colleagues at the NHS Wheelchair Clinic understood your personal needs and worked with you to ensure your wheelchair was suitable?* The data shows that when young people felt NHS colleagues had understood their needs and worked with them, they gave their NHS wheelchair much more positive scores (85%) than negative (4%). The inverse is also true – those who felt colleagues didn't understand their needs and didn't work with them scored their NHS wheelchair more poorly (66%) than favourably (8%).

Needs met by involvement



Following this, young people were asked if there was any particular aspect of life where they felt their NHS wheelchair did a really good job of enabling them. Responses to this question were themed and are displayed in the table below. Each response could contain more than one theme.

Theme	Percentage of responses
Negative response	36%
Access outside the home	17%
Postural support	13%
Meets lifestyle needs	10%
Independent mobility	8%
Access to education	7%
Meets general needs of the young person	4%
Supports symptom management	3%
Improves wellbeing	1%

It was most common for respondents to offer a negative response to this question, highlighting where their wheelchair falls short. In total, more than a third (36%) of respondents mentioned left a negative comment to this question.

- *“Even when fully charged doesn’t last very long approximately 3/4 hrs if have continuous use. Having problems with stalling at times.”*
- *“No, it was useless so we had to self-fund an off-road wheelchair that suited my daughters needs better”*
- *“Unfortunately, I don’t feel that my son’s NHS wheelchair is working well for him. It is too heavy, it slips on the bus even with the brake on, and the footplate is too small to support his legs properly. Because of this, it has not been enabling him in daily life, instead, it has caused difficulties and even injuries.”*

The next three most common responses saw young people and their families finding their NHS wheelchairs enabled them access outside the home, offered postural support and met lifestyle needs (housing, car, carers etc).

- *“Supported sitting posture better than previous mainstream buggy, folded for car, supportive for eating in.”*
- *“The PWB enabled variety to top me up to a suitable lightweight chair for college and everyday living. It changed my life. I could now get through doorways at home and manage huge steps by tipping myself. Life changer. But the NHS chair offered was horrendous. Heavy. Mum could not lift it, and I could not manage to lift it when starting to drive.”*
- *“It got me out of the house when I was housebound”*

- *“Since getting a moulded seating system it really helped her be able to sit in other chair for a longer period of time and so be able to access things and activities for the field and for longer distances.”*
- *“It’s small which helps in manoeuvring at places, people’s homes etc.... But is too small and not supportive enough. It’s twisted for the 3rd time so her back/hips not symmetrical after all these years of trying to help her hips stay solid !?”*

In contrast, the following question asked if there was any particular aspect of life where their NHS wheelchair holds them back or is a hinderance. Responses to this question were themed and are displayed in the table below. Each response could contain more than one theme.

Theme	Percentage of responses
Ill-fitting	63%
Unsuitable for lifestyle	45%
Limits independence	19%
The equipment is just inappropriate	15%
Carer’s ability has not been considered	11%
Wait for repairs is too long	9%
Negative health consequences	5%

The three main themes for this question were NHS wheelchairs being ill-fitting, unsuitable for the young person's lifestyle, and limiting independence.

- *“Yes, uncomfortable so lots time out. Head support inadequate so not supported.”*
- *“It’s flimsy, too heavy, rickety, breaks often, slows her down. She is an extremely active user and uses the chair on all kinds of terrain. It just isn’t robust enough.”*
- *“Not being able to self-propelled wheelchair is extremely limiting. Means he constantly needs a carer to move himself away. Further limits his independence. Wheelchair fits poorly. Legs are far too forward and are at an odd angle. This makes sitting in the chair tiring, difficult to get into and causes pain.”*
- *“It is a very heavy chair bulky hinder us as not worth getting it in and out of the car to go into a shop has parts on that hurts him overall could do with a smaller chair waiting on the specs appointment but could be months”*
- *“it’s very big, very heavy and difficult to control”*
- *“He can’t go anywhere in the car as the wheelchair don’t fold down so we can’t take the chair with us has to be somewhere we are able to carry him a few steps to the local park to the swings and he slides down in his wheelchair causing himself to strangle himself in the chest strap and also they have refused to give him a crotch strap to stop him falling down despite so many services and school getting touch to address the problem!”*

- *“My child is restricted from his independence as he is always having to rely on someone to push him or even turn him around so that he can be part of other children's play. We have been refused a powered wheelchair as the house has not been adapted. he needs a powered chair for his independence.”*
- *“Interacting with my peers and friends. Transferring is really tough. I don't feel safe in my chair and it was extended illegally so I don't have a lap belt or a cushion that fits the dimensions created.”*

Suitability of equipment

Suitability of equipment is subjective, meaning different things to different people. We asked young wheelchair users and their families to tell us what suitable meant to them when talking about their equipment. Their answers have been themed in the table below.

Theme	Percentage of responses
Meets the individual's needs	45%
Good comfort and posture	34%
Fits well and is safe	23%
Lightweight, easy to use and manoeuvre	17%
Promotes independence	16%
Enabling	15%
Promotes social and school life	12%
Meets carers/family needs	9%
Easily transported in the car	8%
Makes daily tasks possible	6%
Improves pain and fatigue, not makes them worse	4%
Personalised or unique	4%

By a considerable margin, the most important consideration for what makes equipment suitable to a young person was meeting their individual needs. This was followed by good comfort and posture and fits well and is safe.

- *“Suitable for more aspects of daily life than not, including ability to interact with home life and accessibility within the home and community.”*
- *“A chair that doesn't make its presence felt and does its job supporting my daughter to be happy, healthy and herself.”*
- *“It works well for what you need it for, it fits well and is the right sizes.”*
- *“I would define 'suitable' as meeting all of the needs of the user and their family. wheelchair services sees it as meeting the absolute bare minimum.”*

- *“A chair that is enabling e.g. allows the young wheelchair user to access what they want/develop not disabling. The is light weight, Easy to use/manoeuvre, and meets needs.”*
- *“Suitable means it meets all your needs and allows for the prospect of physical development and increased ability to propel oneself, adapting to the individuals’ personal needs.”*
- *“Doesn’t produce additional barriers beyond the barriers of being physically disabled.”*
- *“I would say a suitable wheelchair is one that gives you the correct support, such as posture support from backrest, and pressure support from cushion, and a wheelchair allows you to do the things you would do even if you were able bodied. This includes it being a suitable weight for manual chairs, or having the correct support from power, or power assistance to be independent. A wheelchair should give you more freedom, not hold you back.”*
- *“Based on the needs of the child both past and present. And takes into account that the easier and lighter to move the more freedom and progress can be made.”*

Final comments

The last question in the survey asked respondents if there were any further comments they would like to make about the suitability of NHS wheelchairs or about their experiences interacting with NHS Wheelchair Services. Responses were categorised into the following themes:

Theme	Percentages of responses
Limited equipment matrix/lack of options where cost is valued over needs	45%
Long wait times/slow to make repairs or conduct reviews	30%
Colleagues did not understand our needs/did not listen to us	23%
Poor communication	13%
Criteria is too strict	7%
Issues with PWB	7%
Had to self-fund a suitable wheelchair	5%
It is a good service	5%
No accessories provided	2%

Some of the comments provided in answer to this question include:

- *“Due to lack of options offered, often patients and their parents/carers must first do a lot of prior research to know what options may be best for the patient and hope that the NHS professionals agree.”*
- *“It depends who you see I have had some lovely appointments then one time a terrible one, where lady more interested in her phone and answering it.”*
- *“Everything is revolved around budgets/costs of chair not what is best suited to each individual”*
- *“the process has been fairly quick & made simple, I feel confident they’re always at hand to help with any issues & have a really good understanding of the importance of wheelchairs & getting it right”*
- *“We have always found them very unhelpful as they are aware of my strength issues and my parents health, they don’t listen and give me the cheapest chair they have, which really effects my life.”*
- *“When my Wheelchair breaks it takes a very long time to get it repaired. There seems to be no urgency in helping me get back to my normal life, instead I’m told to stay in bed and stay at home or they can lend me a basic foldable wheelchair, which would in no way be suitable for me. It is a horrendous contingency plan.”*
- *“The primary concern of the WCS is to not spend any money and when pushed spend the smallest amount possible to tick a box of providing a metal frame with four wheels and a cushion of sorts. WCS have no compassion. They have no consideration for all the other equipment that parents buy privately (far exceeds any disability benefits and we are limited in how many hours we can work to pay for expensive equipment as there is no care available when out of school). WCS are not interested in working with parents to find a good solution. I feel they offer a poor quality option and hope we will go away and apply to charities.”*
- *“I think that NHS wheelchair services employees need to have greater understanding and training regarding different additional needs and how this relates to the features of a wheelchair needed, e.g. some need more active chairs, whereas others need priority of postural support. I and many others often feel that NHS wheelchair services often go for the cheapest option rather than assessing the most suitable chair, leaving wheelchair users without appropriate equipment.”*

Discussion

A clear take away from the survey is that the experience of accessing NHS Wheelchair Services is very inconsistent. There was a wide spectrum of views, with some young people and their families content with their experience and others wholly dissatisfied. However, the general trend of responses showed there was overall negative sentiment toward NHS Wheelchair Services coupled with instances of NHS colleagues doing the best they could with the resources available, creating pockets of good practice.

Guidance versus reality

Nearly every example of previous policy guidance published across the last 15 years highlights the same shortcomings around NHS Wheelchair Services; a lack of choices, decisions rooted in the medical model, little consideration for holistic needs and lifestyle, long waiting times and delays, and too greater emphasis on cost saving. Each iteration of guidance, from the 2017 Model Service Specification to the 2025 Wheelchair Quality Framework, seeks to address these issues and create a service which delivers more personalised, timely support and provide equipment that better meets the holistic needs of the user.

These aspirations and goals for NHS Wheelchair Services match well with what families are asking for. Across their responses, young wheelchair users and their families said, to them suitability meant a wheelchair that fits the individual's needs, offers good comfort and fit, is easily manoeuvred and promotes independence. Those who said they had a positive experience during their clinic visits felt they had been listened to, and that their needs had been considered. They agreed that their wheelchair fit well and was adapted to meet their needs, and NHS colleagues were characterised as helpful and informative. All of the above indicates that families are largely in agreement with NHS guidance on what a good service should consist of.

Despite the consensus on expectations, this unfortunately did not always match the reality for many families. In fact, many of the issues young wheelchair users and their families report in their survey responses still mirror those long-term issues - excessive waiting times and delays, a lack of choice, equipment not meeting needs, too much emphasis on cost saving, and not enough consideration of individual lifestyles. Despite the introduction of new guidance over the last decade, it would seem that, in the eyes of young wheelchair users and their families, little to no change has occurred in how NHS Wheelchair Services function.

Suitability of equipment

In certain aspects, the equipment provided by NHS Wheelchair Services was deemed to be suitable by young people and their families. NHS equipment was scored most positively on meeting medical, functional and educational needs by young wheelchair users.

However, equipment provided by the NHS was scored more poorly when it came to meeting family, social, employment, and physical and postural needs.

Back in 2014, *Right Chair, Right Time, Right Now* found that “users stated that they want equipment decisions made on a social rather than a medical model of disability, to take account of all their needs. This was often felt not to be the case”²⁹. The results of the survey seem to show that this approach to prescribing equipment still rings true. Respondents shared that generally their equipment better supported their more traditional medical needs. Whilst it is undoubtedly important that these needs are met, those wider, more holistic areas such as employment, social and family needs scored more negatively. Again, this shows a gap between the guidance and reality. The guidance seeks to make holistic needs, personal goals, and individual lifestyle a focal point of delivery, but this is not currently being realised. The same finding was noted in the report *An Economic Assessment of Wheelchair Provision in England*, which found that the “focus of NHS provision is generally on clinical needs due to the levels of funding provided”³⁰.

However, there could be some progress in this ambition for a more holistic service in educational needs. Young people scored their NHS wheelchairs more positively when it came to enabling them to attend school, college, sixth form and university, with 43% giving a positive response compared to 27% that gave a negative response. Often through no fault of their own, absence rates are higher amongst disabled pupils; in 2022-2023, students with Education Health and Care (EHC) plans missed 12.3% of sessions compared to only 6.6% of students without Special Educational Needs or Disabilities (SEND)³¹. Pupils with EHC plans were persistent absentees from school at almost twice the rate of pupils without SEND³². Statistics also show that disabled people are more likely to have no qualifications and are less likely to hold a degree³³. Any actions that can be taken to enable young wheelchair users to engage more with educational opportunities will be of great benefit. As the *Whizz Kidz Making the Grade* Report concluded, more must be done to ensure all young wheelchair users have equal opportunities at school³⁴.

Despite all of this, the positive scores of equipment remained subdued across the board. None of the seven aspects on which young people and their families were asked to score their wheelchair saw a standout positive response. In all cases, less than half of respondents felt positively about their wheelchair, with the highest percentage of positive sentiment reaching only 45%. The message here is clear – the equipment provided to young wheelchair users by the NHS is not hitting the mark.

A little over half of the respondents to complete the survey were able to share what kind of wheelchair they were provided with by the NHS, and this information enabled comparisons to be drawn between datasets. The model of wheelchair prescribed did result in some differences on how positively or negatively young people scored their wheelchair for meeting their different needs. Tendercare Snappi buggies were least favoured along with Sunrise Medical Argon models and Invacare Action models. Notably, of those who received an Action model wheelchair, only 3% said that colleagues at NHS clinic had definitely understood their needs and worked with them, compared to 45% who

said they didn't understand their need or work with them at all. Similar was true of Tendercare Snappi buggies – just 10% responded definitely to this same question whilst 40% responded not at all.

There are 16 categories of wheelchair that the NHS provides and 31 manufacturers that supply the equipment according to the NHS product matrix³⁵. Invacare supply models of wheelchairs across 15 of the 16 listed categories and Sunrise Medical supply models across 13 of the 16, giving them the most breadth of suppliers. When isolating just the five listed paediatric categories of wheelchairs, Invacare supply wheelchairs across all five categories and Sunrise Medical across four – again, giving these manufacturers the greatest breadth across categories of paediatric wheelchairs.

This is reflected in the brands of wheelchair supplied to young wheelchair users – 70% of young people who could tell us what type of wheelchair they received were provided with a wheelchair manufactured by either Sunrise Medical (38%) or Invacare (32%). It would appear that Sunrise Medical and Invacare therefore hold a monopoly on the NHS supply of wheelchairs to young people, with 70% representing a considerable majority. It was noted in the research that, as a result of economic pressures, wheelchair services are buying standardised equipment in bulk more frequently³⁶. This could account for a high percentage of young wheelchair users receiving equipment from these two manufacturers.

It is essential to note that when NHS Wheelchair Services do get it right, the benefits to young wheelchair users and their families are immeasurable. Young people who felt their wheelchair was largely successful in meeting their needs said their wheelchair brought them freedom and independence, allowed them to access more opportunities in school and in their communities, and offered good postural support and comfort. Across all respondents, young people who felt that NHS colleagues had understood their needs and worked with them provided far more positive scores on how well their wheelchair met their various needs. This creates a strong case for including young wheelchair users and their families in the process of assessment and choosing a wheelchair, as they appear much more content in the equipment they are provided when they are involved, listened to and understood.

“Absolutely, this wheelchair has given me freedom to move around, I can independently do things, I am happy.”

“All of them, it's a well made, fairly well fitted lightweight chair, no complaints.”

“Son unable to sit, stand, etc but can drive with tongue or chin so strapping him in gives freedom.”

Choices, involvement and understanding needs

There were two key points that continually arose throughout the survey and the various guidance documents – choices and involvement, and understanding of needs. The guidance determines that understanding of needs is paramount to service delivery and that wheelchair users should be offered greater choice and involvement, yet in their survey responses young wheelchair users and their families found both areas to be lacking.

The survey results reveal a substantial appetite for more choices and greater involvement of young people and their families in the process of assessment and prescription of a wheelchair. Young wheelchair users have reported a lack of choices and involvement across all aspects of the process, from selecting a make or model of wheelchair, to being given the option of a PWB, and to customising their wheelchair:

- 77% were not given any choice at all on the make or model of wheelchair they received.
- When asked what could have been better, 19 respondents said they were not given enough involvement in the process and 12 said there was a lack of choice of equipment.
- 72% of young wheelchair users were not given the option of PWB.
- 62% said they were not able to customise their wheelchair in anyway.

Additionally, understanding of needs was also consistently raised as a point of contention. Young wheelchair users and their families frequently found that colleagues at NHS Wheelchair Services did not fully understand their personal needs when assessing and prescribing a wheelchair:

- When asked “do you feel that colleagues at the NHS Wheelchair Clinic understood your personal needs and worked with you to ensure your wheelchair was suitable”, 32% of respondents said not at all.
- When asked what could have been better, 71% respondents said the equipment provided was ultimately not suitable for them.
- A considerable proportion of young wheelchair users scored their wheelchair negatively when it came to meeting their physical and postural needs (43%), their employment needs (26%), their social needs (45%) and their family needs (51%).
- At the end of the survey, respondents were provided the opportunity to share any other comments they had – nearly a quarter (23%) of respondents said that colleagues at NHS services did not understand their needs and did not listen to young people or their families.

The Care Quality Commission expects providers, commissioners and system leaders to live up to the following statement: “we promote people’s independence, so they know their rights and have choice and control over their own care, treatment and wellbeing³⁷”. They state that in practice this means supporting people to make their own decisions, communicating clearly their rights, and providing a “range of appropriate equipment to

support and maximise people's independence and outcomes from care and treatment"³⁸. By definition, person-centred care focuses on the needs of an individual and is responsive to a person's circumstances, values, needs and preferences³⁹. Person-centred care holds many benefits too, such as improving patient experience, care quality and health outcomes⁴⁰.

The strategic direction of NHS Wheelchair Services, as set by the guidance and framework outlined in the background research section of this report, hinges largely on these two areas. From their survey responses, it would seem young wheelchair users and their families feel strongly about the importance of choice, involvement and their needs being understood by NHS colleagues. Across the survey, respondents linked an understanding of needs and being given choices and involvement in the process as indicators for successfully receiving a wheelchair they felt was suitable. The reverse was equally true – where respondents felt there was a lack of choice and involvement and a lack of understanding of needs, they felt their experience and the equipment received was poorer. It is therefore imperative that NHS Wheelchair Services close this gap and marry real life experiences to the theoretical guidance.

Conclusions

Across more than 200 responses, young wheelchair users and their families generally expressed more negative sentiments about their experience of accessing NHS Wheelchair Services than positive. Young people often felt their needs were not completely understood and that the equipment they received was not always suitable. Young wheelchair users reported that they were not given sufficient involvement and agency throughout the process of assessment and prescription. Responses also highlighted long waiting times and a lack of holistic thinking and consideration of individual lifestyles. Young people and their families often got the sense that more emphasis was being placed on saving money than providing the right or best equipment for the wheelchair user.

This is all despite the existence of a variety of specifications and guidance documents that should see NHS Wheelchair Services placing these factors at the forefront of their service delivery. It is clear the NHS has reflected upon past critiques of its wheelchair services and made changes based upon this, however the policy and guidance introduced in the past decade have not impacted on young wheelchair users and their feelings towards NHS Wheelchair Services. Whilst there were instances of young people receiving equipment that suited them well, these were in short supply as isolated incidences of best practice rather than clear or widespread trends across respondents.

It is essential that young wheelchair users receive the right equipment and equipment that enables them to access opportunities in life. Young people are full of potential and are eager to be independent, learn, grow and contribute to society at large. The impact of the right equipment truly cannot be overstated.

The aim of this report was to assess the suitability of the equipment provided to young wheelchair users by NHS Wheelchair Services. Given the evidence, we would conclude that the equipment provided is currently not meeting needs. Whilst there were aspects where young wheelchair users scored their wheelchair more positively, not one of the seven areas of need – medical, functional, physical or postural, educational, employment, social or family – received a positive score of more than 45%. This, combined with the comments and general tone of responses, indicates that young wheelchair users are left wanting by the wheelchairs they have received from the NHS.

Further changes to NHS Wheelchair Services are needed. It is imperative that any change has real, measurable impact on young wheelchair users, their families, and their experience.

Recommendations

Review NHS Wheelchair Services and their commissioning

It is clear from our research that young wheelchair users are not receiving the equipment they need. Whilst the guidance generally reflects what young people say they want from NHS Wheelchair Services, this is not being translated into practice.

Our Ask: The Government should review NHS Wheelchair Services, including how they are commissioned, to determine why services are not currently meeting expectations despite the existing guidance and create an action plan for improvement.

Paediatric training for colleagues at NHS Wheelchair Services

Children and young people grow and change quickly – it is essential that they receive equipment that supports their ongoing development. Training should reinforce the importance of listening to and working with young wheelchair users, involving them in the process, and giving agency and choice wherever possible. Current NHS guidance already recommends this approach, and training could help to bridge the gap between guidance and reality.

Our Ask: Colleagues working within NHS Wheelchair Services should be provided with standardised and regular training on working with and prescribing equipment for paediatric patients.

Capture and review feedback and action change accordingly

It is essential that meaningful feedback is captured, reviewed and used to inform change to NHS Wheelchair Services. Feedback should be based around outcomes that are important to young wheelchair users and reflect the holistic approach that services should aspire to.

Our Ask: The Government should capture feedback and analyse this to improve NHS Wheelchair Services according to young wheelchair users' experiences. This will be monitored and the voice of young wheelchair users will be essential to confirming if change has been successful.

Supporting young wheelchair users to self-advocate

Whizz Kidz will work with young wheelchair users and their families to help them to advocate for their needs. It is important that young people and their families can effectively recognise and communicate their wants and needs to NHS colleagues to help make sure the equipment they receive is right for them.

Our Commitment: Whizz Kidz and the Youth Board will support young wheelchair users in learning to advocate for themselves and being confident in expressing their needs.

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Appendices

Appendix 1: Types of NHS wheelchairs

Manual: a manual wheelchair is not powered or motorised in anyway. Compared to a powered wheelchair, manual models are often lighter, easier to pack away and more affordable.

Powered: a powered wheelchair uses battery power and an electric motor to move forward. They can be controlled by either the wheelchair user or by an attendant depending on the needs of the wheelchair user, the model of wheelchair and its configuration. Powered wheelchairs are often larger, heavier and more expensive than manual wheelchairs.

Special needs buggy: unlike a standard buggy, a special needs buggy provides postural support and are often more robust with a higher weight capacity.

Self-Propel: a self-propel wheelchair is one type of manual wheelchair. It is moved by the wheelchair user turning the wheelchair with their hands. Self-propel wheelchairs have large back wheels to enable this.

Attendant or transit: another type of manual wheelchair is an attendant or transit wheelchair. This is designed to be pushed by another person. It has small rear wheels that cannot be used by the wheelchair user themselves to move.

Tilt in space: a tilt in space wheelchair supports postural needs and manages pressure distribution. The entire seating system, including the seat itself, backrest and leg rests, can be rotated and fixed in space to suit its user.


Lightweight and ultra-lightweight: a lightweight wheelchair can weigh between 8-15kg. Due to their lower weight, they require less effort to use and are easier to lift, store and transport. An ultra-lightweight wheelchair weights even less.

Appendix 2: Frequently prescribed models of wheelchair

Invacare Action models


Model	About	
Action 2	The Action 2 is a folding manual self-propel wheelchair. The Action 2 weighs between 15-17kg.	
Action 3 Junior	The Action 3 Junior is a paediatric model. It is a manual self-propel wheelchair and weighs 14.5kg.	
Action 3	The Action 3 is a rigid manual self-propel wheelchair. The average weight of this chair is 14.5kg.	
Action 4	The Action 4 is the most durable Action model, weighing 14kg. It is a self-propel wheelchair.	

Sunrise Medical Argon models


Model	About	
QUICKIE Argon 2	The Argon 2 is a lightweight (8kg) rigid self-propel wheelchair.	

Sunrise Medical Q models


Model	About	
QUICKIE Q200 R	The Q200 is an ultra-compact powered wheelchair. It weighs 98kg and has a fold down back.	
QUICKIE Q300 R	The Q300 is a powered wheelchair weighing 136kg with rear-wheel drive.	
QUICKIE Q300 M Mini Teens	The Q300 Mini Teens is a powered wheelchair with growth-adjustable seating and mid-wheel drive. It weighs 103kg.	


Model	About	
QUICKIE Q500 M	The QUICKIE Q500 M is a powered wheelchair with mid-wheel drive. It has a starting weight of 120kg.	

Sunrise Medical Simba model

Model	About	
ZIPPIE Simba	The ZIPPIE Simba is a lightweight (8kg) rigid children's wheelchair	

Tendercare buggy models

Model	About	
Snappi	The Snappi buggy is a tilt in space special needs buggy. It is lightweight (22kg) and foldable.	

Model	About	
Snazzi	The Snazzi is a tilt in space special needs buggy. It is lightweight (15kg) and foldable.	



We're here
for young
wheelchair
users

If you want to get in touch with Youth Board or Whizz Kidz about this guide or any other way you feel we can support young wheelchair users, please contact us.

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