Wheelchair Alliance

Transforming the lives of wheelchair users

Election Manifesto

About the Wheelchair Alliance

Formed in 2015, our vision is to transform the experience for wheelchair users in England through improved access, quality and effectiveness.

We are committed to hearing the voice of wheelchair users, providing information to empower those who use a wheelchair, their families and carers. Over the last three decades there have been many reports, reviews and recommendations in relation to wheelchair services made by Government, statutory and voluntary services sectors. These all indicated that there was considerable variation in wheelchair services and provision across England.

Since 2020, the Wheelchair Alliance has been busy reviewing, refreshing and reinvigorating its commitment to wheelchair users and their carers. In 2021 the independent Wheelchair Alliance Community Interest Company was formed to strengthen the voice of wheelchair users, working in collaboration with commissioners and providers to make lasting positive change.

Much has been achieved although there is still a long way to go. This is our manifesto, outlining what we expect from commissioners and wheelchair services going forward.

Five-point plan for immediate action



1: FAIR REPRESENTATION

Ensure voices of wheelchair users are heard

Action needed: development of the Quality Framework for Wheelchair Provision in collaboration with NHS England, ensuring that the voices of wheelchair users are listened to. To be swiftly approved with clear action for Integrated Care Boards to work to the framework.



2: BETTER FUNDING

Review of current investment

Action needed: for the new Government to increase funding levels into wheelchair services. Based on our independent findings, investment is needed, alongside central ownership within government.



3: STANDARDISED WHEELCHAIR PROVISION

Remove current inequalities

Action needed: update and adopt the Model Service Specification for Wheelchair and Postural Seating services to ensure the standardisation of service provision, regardless of location. Lobby new Government regarding the development of a standalone All-Party Parliamentary Group for Wheelchairs and Postural Management.



4: MANDATED REGULATION

Instigate a more rigorous approach

Action needed: ensure all NHS organisations and contract providers are subject to more rigorous, mandated regulation through an independent body.



5: ACCURATE DATA

Identify existing gaps and true levels of demand

Action needed: future data capture to be meaningful and comparable across all Integrated Care Boards, with all service providers submitting quarterly data without exception. This data to be monitored and challenged where indicated to allow existing and future skills gaps to be filled.

Foreword

Baroness Tanni Grey-Thompson



Tanni Grey-Thompson
President, Wheelchair Alliance

About Tanni

A wheelchair racer and retired Paralympian, Tanni is a fierce campaigner when it comes to wheelchair provision. Recently appointed as president of the Wheelchair Alliance, she is also a member of the House of Lords, which enables her to use this platform to highlight the views of wheelchair users.

I don't think people really understand how important wheelchairs are. As one of the founder members and president of the Wheelchair Alliance, I've campaigned tirelessly on a number of prominent issues including accessibility, equality and welfare reform.

Since its launch in 2015, the Alliance has brought together wheelchair users, charities, representatives from the NHS and trade to highlight the challenges faced by wheelchair users every day.

And as a disabled person I try to explain to people what my chair means to me. It's not 'a' wheelchair, it's 'my' wheelchair. It's how I want to sit. It's how I want to look. Without it I couldn't do anything, so it means everything to me.

Being a wheelchair user often means that you need to be an expert in everything, whether it's education or work or welfare or social care and a lot of the time it feels like you are having to make compromises. That's something wheelchair users should not have to do.

Those who are disabled, along with their families, shouldn't have to be the experts simply because the system doesn't work.

The Alliance's latest report, the Value of a Wheelchair, highlighted the huge disparities in the time it takes for people to access wheelchair services and the support they need.

Alongside this is the cost; but it should be about investment, as the cost of not getting it right is actually terrifying. It's not just financial but it's the emotional cost, the psychological cost, the cost to society of not making it right and not making it possible for people to be integrated in.

Something must change. It has been ten years since I posed for pictures outside parliament in a wheelbarrow to highlight how many disabled people are being provided with inadequate wheelchairs by the NHS – and we are still pushing for change.

It’s vital people get the right chair, at the right time. And this is what I’ll be calling for the new health secretary to focus on.

The huge variation in quality of services across the UK is astounding and means a huge proportion of wheelchair-users are left immobilised, frustrated and ignored.

Of course, we can’t force NHS England to accept recommendations. That is why we need enough evidence and support to get wheelchair service improvement in the NHS mandate.

It's a shame we need to campaign for this at all; but the reality is that we do. Due to the restrictions facing services, we often see inadequate service, alongside pockets of good, and it is time that wheelchair-users are listened to and provided a proper service, rather than being marginalised.

For me, it’s not just personal, it’s about getting it right for everybody and doing the right thing.

Executive Summary

Nick Goldup



Nick Goldup
Chair and Chief Operating Officer, Wheelchair Alliance

About Nick

Nick Goldup took-up the helm at the Wheelchair Alliance following many years as a director within the charity sector, including six years as director of care improvement at the MND Association and five years at Whizz-Kidz, a charity which provides wheelchairs and support to more than 10,000 children across the UK. Nick was one of the co-founders of the Alliance in 2015.

The Wheelchair Alliance is a not-for-profit organisation which champions the needs of wheelchair users across England. I have been chair of the Alliance since 2020 and became chief operating officer in March this year to help further strengthen the voice of wheelchair users who face significant challenges when it comes to accessing wheelchair services.

Since my time at the Alliance, it's clear that current funding, which is the equivalent of £196 per person per year for wheelchair users, is just not enough.

The reason is because those commissioning wheelchair services do not fully understand the level of funding needed; there simply is not enough data to show the levels of demand. This is largely due to the lack of money in the system along with the eligibility criteria for getting a wheelchair often being strict and varied across the country.

In England, you are entitled to a wheelchair via the NHS if you meet the local criteria. Some integrated care boards (ICBs) – the local autonomous bodies that determine the policy and budgets for wheelchairs – are having to ration provision of wheelchairs due to a lack of investment over decades, only providing a basic wheelchair, rather than one that meets the individuals assessed needs to lead the independent life they would choose. ICBs can offer a personal wheelchair budget (PWB) towards the payment of a chair, with the individual expected to cover the difference in cost, which often means several thousands of pounds which is not fair and equitable.

Our most recent report, The Value of a Wheelchair, lays bare the postcode lottery which currently exists in wheelchair provision, something we are determined to see change.

Working alongside Frontier Economics and Revealing Reality, the report – made possible through grant funding from The Motability Foundation, for which we are incredibly grateful – considered both quantitative data and in-depth interviews with wheelchair users across England. It unambiguously shows that the provision of a high-quality wheelchair does not only have a significant beneficial impact on people's lives but also leads to financial benefits for the NHS and society. It highlights that, using conservative assumptions, investment in wheelchair services could result in significant positive economic impact at a ratio of approximately £3 benefit across society for every £1 invested.

The research indeed shows that increasing investment in wheelchairs by £22 million per annum, with wheelchairs users provided with the right high-quality wheelchair, would unlock benefits to the UK economy of more than £60 million per annum. Should the annual total benefit be 5%, the same investment would realise benefits to society, including savings to the NHS, in excess of £315 million per annum.

The facts speak for themselves but what is more far-reaching is the stories of wheelchair users of all ages, from children and young adults through to the elderly, who have spoken about the challenges they face in receiving better wheelchair provision, services, and policies.

We all know that the NHS is not operating as well as it can be. However, we will not be drawn into a 'blame game.' We can only bring about lasting, positive change through collaborating with NHS England, the Government and other health and social care organisations.

Our job at the Wheelchair Alliance is to lobby for wheelchair users and become their voice, which is why we are launching our five action points and our Wheelchair Alliance membership, which will enable people to join the movement and make change. It is free for wheelchair users and will give those signing up access to a range of benefits and online resources, while supporting the Alliance in our mission to influence Government and healthcare providers into recognising the importance of timely and appropriate wheelchair provision.

The Wheelchair Charter, a set of six principles that seek to ensure that everyone who needs a wheelchair gets one, should be considered as a benchmark of best practice for independent, third sector and private providers of similar services. It was written to influence the provision of NHS commissioned and/or tendered out wheelchair and postural seating services and the Alliance's guide to the Charter aims to help ensure all wheelchair users receive the best wheelchair for their assessed needs.

The incoming Government also has an opportunity to put this right. And, when they do take steps to do this, we want to be a part of those conversations. Wheelchair users deserve so much more, and we will continue to collaborate with our partners at the highest level to drive improvements forward.

FAIR REPRESENTATION



Ensure the voices of wheelchair users are heard

Here at the Wheelchair Alliance, we want to transform the experience for wheelchair users in England through improved access, quality and effectiveness of services.

We plan to do this by ensuring the collective views of wheelchair users are represented with all relevant organisations and work in partnership to influence at the highest level, ensuring wheelchair users are empowered to lead qualitative, independent lives. This will be done by making sure wheelchair users are listened to and have confidence that every wheelchair service provides the choice and capability to fully deliver the outcomes of each individual person.

Services and processes that demonstrate best practice for wheelchair users and, where appropriate, their primary carers/families, will continue to be publicly supported and championed by the Alliance.

In addition, we believe that by expanding the community of wheelchair users with representatives from all areas of the country will further help support development of information for people needing a wheelchair, reaching those who do not access wheelchair services. Information about Personal Wheelchair budgets will be presented in a way that has jargon removed and can be endorsed by both our user engagement group and health and social care organisations.

Our website will also act as a gateway to external policies, procedures and practice while a quarterly newsletter will be published, featuring information that best supports wheelchair users and their primary carers/families.

Our Recommendations:

1. Develop a national advisory board of wheelchair users, with representatives from each of the seven NHS regions. This will enable us to amplify the voice

of those with lived experience, lobbying at the highest level using relevant data and information.

2. Review the Wheelchair Charter, or its equivalent, following the delegation of responsibility to Integrated Care Boards (ICB) and use it in conjunction with the Quality Framework for Wheelchair Provision to hold relevant stakeholders to account.

3. Launch of a standalone All-Party Parliamentary Group (APPG) for Wheelchairs and Postural Management to strengthen the voice of wheelchair users in Parliament using a forum of cross-party MPs and Peers to influence at the highest level.

4. Ensure the voices of wheelchair users are represented during the development of the Quality Framework for Wheelchair Provision.

BETTER FUNDING



Review of current investments

Analysis has shown that a relatively modest increase in wheelchair service equipment spend could make a meaningful impact on the budgets of Integrated Care Boards (ICBs) who are currently reporting below average per patient spend on equipment budgets. This increase in spend would deliver significant cost benefits.

There is also a need to ensure that current budgets are used in the most effective way possible. This includes the sharing of best practice between commissioners and realising the advantages of joined up working and pooled budgets by statutory bodies for the benefit of wheelchair users, their families and carers.

The Value of a Wheelchair report indicates that Government funds spent on wheelchair users equates to an average of £196 per person per year, which includes the cost of a wheelchair, expert support as well as infrastructure costs. This level of underfunding has remained the same for at least five years.

However, it is key that the new Government reviews the current investment levels into wheelchair services to ensure that any increase in spend delivers significant cost benefits, as well as identify the annual spend on wheelchair and postural seating services over the last ten years.

With approximately three million people impacted, the right amount of funding is crucial in being able to make life changing difference to wheelchair users. It will also bring a reduction in cost over time for the NHS (particularly with regard to child and adult mental wellbeing) and an increase to the Exchequer as people are enabled to go to work. This is also true for those aged over 60 but who are below the retirement age of 67, who require a wheelchair in order to continue independence in employment.

Our analysis shows that a relatively modest increase in wheelchair service equipment spend could make a meaningful impact on the budgets of ICBs who are currently reporting below average per patient spend on equipment budgets. This increase in spend would deliver significant cost benefits.

In order to deliver this recurring benefit, appropriate funding is required with The Value of A Wheelchair report clearly showing that investment of £22m per annum will deliver a minimum return of £60m per annum, although this is believed to be nearer to £315m per annum.

Our Recommendations:

1. Urgent review of current funding levels to help protect wheelchair service provision.

2. Department of Health and Social Care (DHSC) and NHS England to commit to increasing the current spending on NHS wheelchair services to help ensure more benefits are realised and the NHS can unlock significant cost savings.

3. Current budgets to be used in the most effective way possible, to include the sharing of best practice between commissioners who are knowledgeable in the complex provision of wheelchair and postural seating serviced, therefore realising the advantages of joined up working and pooled budgets by statutory bodies; all for the benefit of wheelchair users, their families and carers.

STANDARDISED WHEELCHAIR PROVISION



Remove current inequalities

There are clear advantages to locally led provision of NHS wheelchair services. In particular, commissioners can provide a service which is tailored to local needs. However, this has led to variation in the standard of care provided and service user experience. This variation has been highlighted in previous studies and the Alliance's in-depth engagement with wheelchair users re-emphasises this inequality. Service users reported that they were often left to navigate the system themselves and had to rely on their own experience and knowledge to access support.

Although NHS England has worked in partnership to develop a service specification for wheelchair services which is an effective guideline, it is non-compulsory. Therefore, there are significant variations in structure and delivery between areas of England.

According to the report, wheelchair users are categorised into three levels of assessment/intervention criteria: low, medium and high. There is significant confusion over how these categories are interpreted, with some wheelchair users feeling there could be some discrimination. Ultimately, commissioners need to be better educated about wheelchair users in their region and ensure individual needs are considered holistically.

In addition, providers currently interpret the specification to their local community or available budget, and this can sometimes lead to inconsistencies in provision. Therefore, a more nuanced and tailored approach is required.

Our Recommendations:

1. New Government to review current investment levels into wheelchair service which have not altered in decades – and which have been severely impacted by both austerity measures and the cost-of-living challenges.

2. Development of a standalone All-Party Parliamentary Group for Wheelchairs and Postural Management to ensure ICBs and commissioners have a full understanding of what they need to provide.

3. Work collaboratively with NHS England and the National Wheelchair Advisory Group to develop the Model Service Specification to ensure it becomes more than guiding principles.

4. Work in partnership with wheelchair users, manufacturers, policy makers, NHS England, Integrated Care Boards (ICBs) as well as local commissioners and service providers to improve services and equipment that best support independent living.

MANDATED REGULATION



Instigate a more rigorous approach

The Wheelchair Alliance believes a more rigorous approach to standards is essential with the need for an independent regulator.

The Value of a Wheelchair report raises concerns that wheelchair users may be being exploited due to a lack of clear regulation, independent review body or information about who to approach regarding repairs, complaints or suggestions for service improvements. Indeed, a recent intervention from the Health Ombudsman has reinforced this concern.

Therefore, the Alliance is committed to working with NHS England and providers to develop a simple system for wheelchair users, their families and carers to help them get repairs, feedback and make suggestions on service improvements. It is key that these issues should be led by wheelchair users themselves through wheelchair user groups linked to each service.

The Alliance will also investigate the possibility of a regulatory body with oversight for all wheelchair and postural management services, or lobby for a National Institute of Health and Care Excellence (NICE) guideline for wheelchair and postural management.

NHS England also needs to play a more active role in ensuring that all ICBs prioritise wheelchair services and dedicate sufficient resources to effectively deliver the service. For example, this could be done by mandating that all ICBs adopt the Quality Framework for Wheelchair Provision along with the Model Service Specification when commissioning wheelchair services. This would help to minimise inequality across different services and ensure consistent delivery of a good quality service and provision.

Our Recommendations:

1. Ensure all NHS organisations and contract providers are subject to more rigorous, mandated regulation.

2. Mandate that all ICBs adopt the Quality Framework for Wheelchair Provision along with the Model Service Specification when commissioning wheelchair services.

3. Challenge services and processes that do not provide equitable care in an acceptable timeframe.

ACCURATE DATA



Identify existing gaps and true levels of demand

NHS England has worked hard to develop a reporting dataset for wheelchair services. However, this is often inconsistent meaning gaps in service provision are hidden. It is impossible for NHS England and service commissioners to provide appropriate funding and therefore service delivery without knowing the scale of demand.

Unfortunately, this data has been approximated for many years, and therefore it is essential that the issue is urgently resolved so that meaningful and comparable data includes all providers of NHS wheelchair services to ensure that a full picture of service provision is available and reviewed each quarter.

It is only by understanding the true demand on providers for wheelchairs and associated equipment that NHS England can commission appropriate services. Adequate funding requires accurate wheelchair user data so their families and carers can be confident that they will be treated equitably – wherever they live in England. This means all types of wheelchair services must offer regular data based on outcomes to ensure accountability and reduce regional differences.

The Wheelchair Alliance will continue to monitor the provision of wheelchairs and, should there continue to be inequity of provision and choice across England, we will have high level discussions exploring the benefits of a national wheelchair service provision funded through health, social care and education contribution.

Understanding real demand facilitates the robust planning of services where the appropriate number of highly skilled staff such as therapists, rehabilitation engineers and technicians can be forecast correctly, alongside the purchase of high-quality equipment.

There is still significant uncertainty surrounding the number of wheelchair users in England, which is why the establishment of appropriate methods of data collection to support change and enforce the claims made on behalf of wheelchair users, is vital.

Our Recommendations:

1. The new Government and NHS England take steps to ensure all ICBs commission wheelchair services that provide equitable services through robust audit and meaningful data capture overseen by a recognised independent body such as the Care Quality Commission.

2. Future data must include all providers to ensure that a full picture of service provision is available each quarter, which will allow existing and future skills gaps to be filled.

3. Wheelchair Alliance will seek to meet with NHS England every quarter as an independent voice, to discuss the minimum data set commissioners complete to drive service improvement and address recurrent issues behind poor provision.

4. Development of an online resource hub in collaboration with key organisations where professionals can access and share examples of good practice, enabling relevant data to be captured.