NHS
Improving Quality

RIGHT CHAIR RIGHT TIME RIGHT NOW

My VOICE
My WHEELCHAIR
My LiFE

Do we have an intolerable situation with wheelchair services?

This is a review of what the evidence base tell us about the current state of wheelchair services in England, in relation to people with complex and changing needs, and its impact upon people's lives and health, care and voluntary services.

As we have scanned the evidence we have come across information on areas such as funding levels, eligibility criteria and unmet need which were out of scope of this work. We therefore have not included recommendations in these areas.

#Mywheelchair @NHSIQ email: **wheelchairs@nhsiq.nhs.uk**

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FOREWORD

DIGITAL FOREWORD: Click the box on the right to watch a digital foreword from Baroness Tanni Grey-Thompson.

RIGHT CHAIR RIGHT TIME RIGHT NOW

I try to explain to people what my chair means. It's not 'a' wheelchair, it's 'my' wheelchair. It's how I want to sit. It's how I want to look. You can't compare it to a pair of shoes, but not having it would be like stripping me naked and making me crawl. I could not do anything with my life - so the chair is everything to me.

When I became a wheelchair user at seven my doctor said to me "do you know what a pressure ulcer is?" I'd never heard of one. He showed me this picture and it was how it started, which was with this tiny little hole, and then how it blew up, and it was this great big gaping wound that was green and horrible and you could see a doctor putting his hand in it. And he said to me "if you get one of these you will die". It was terrifying. And that has affected every single day of my life, because I don't want my life to end or to be stopped because of not sitting on the right cushion, not having my legs at the right height or not having the right back support.

As a disabled person it feels a lot of the time that everything's a battle and that you need to be an expert in everything whether it's education or work or welfare or social care and it feels a lot of the time like you are having to make compromises. What I want out of this this campaign is actually for disabled people to feel empowered to say 'this is how I want to live my life', 'these are the things I want to do'.

When you see it all in one place, the cost of not getting this right is actually terrifying. It's not just the financial cost, 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.

So that's why I'm supporting RIGHT CHAIR RIGHT TIME RIGHT NOW…. because it can make that difference for everybody.

Baroness Tanni Grey-Thompson

EXECUTIVE STATEMENT

As the Clinical Director at NHS Improving Quality I became aware of the continuing challenges wheelchair users and their carers face in England when pledges to do something about it flooded in during NHS Change Day 2014.[1]

Surveys suggest there are up to 1.2 million wheelchair users in the UK and two thirds of those use a wheelchair regularly to enable them to live their life to the full...

...this is around the populations of Leeds and Manchester combined. This is not a small number and it becomes a big problem when a large number of wheelchair users are not receiving the service that they require to meet their needs.

> "… making my life manageable, keeping me sane and sociable"

Out and About, 2006[2]

As I have reviewed the evidence and become more knowledgeable about the situation faced by wheelchair users and their carers and families, I can see that we have made real progress and we list a selection of organisations doing notable work within this eDigest. However we do still have an intolerable situation where people who use wheelchairs do not get the wheelchair they need, in a timely way, everywhere and every time.

Putting this in context for the wider public:

DELAYS **Would you tolerate a situation whereby essential medical treatment was available and prescribed for you, something necessary for you to live your life to the full, and you had to wait three months for it? I know I wouldn't – yet 70% of wheelchair users have no choice.**

HARM **Would you tolerate receiving the wrong prescription knowing it will cause avoidable side effects that could mean you need to be admitted to hospital? I know I wouldn't - but again many wheelchairs users have no choice.**

WASTE **Would you tolerate paying tax that consistently funds the wrong treatment? Where wheelchair services are concerned, in many cases you are.**

For many people we have spoken to it is frustrating and difficult to understand why this is still the situation, when there have been so many attempts to put it right and when we have such committed staff from all sectors, all working to do their best to make the system work for people who use wheelchairs. The problem we are trying to solve is not about neglect or lack of passion but dealing with complexity, and we need to think differently if we are to really make a difference.

To help us fully understand the issues with wheelchair services, we have been looking at some of the data. It is clear that:

We have **unacceptable delays** for many wheelchair users in getting their chair.

- 70% of wheelchair users wait more than three months for their chair, 30% wait more than six months and 15% wait more than 12 months.
- When people have life limiting illness it is so important we do what we can quickly to get people what they need so the time they do have is quality time. And yet at any one time there are 500 people with Motor Neurone Disease waiting for a wheelchair.

We are **causing harm** by providing ill-fitting or ill-equipped chairs.

- Up to half the number of wheelchair users will develop a pressure ulcer at some point during their life. For up to 100,000 wheelchair users, this will be because they've been given the wrong chair.
- Being given the wrong chair can also impact severely on wheelchair users' mental wellbeing.

We can also cause harm by not taking into account the **needs of carers** when identifying the best wheelchair.

- Parent care givers have a 90% chance of developing musculo-skeletal damage.
- 75% of carers of wheelchair users have no training in how to reduce harm to their health.

These issues cause a great deal of upset and frustration for service users and their families. But the figures also highlight a shocking **waste of public money**. If we get the right wheelchair to the right person in a timely way and provide the right support to wheelchair users and carers where appropriate, we can avoid huge waste for the NHS, and enhance the contribution that wheelchair users can make to the UK economy.

- It costs just £200 - £500 for the right cushion to help minimise the risk of pressure ulcers. When we compare this to the cost of treating a full thickness sacral pressure ulcer, which is about equivalent to the cost of 16 total hip replacements, it doesn't make sense not to provide the right cushion.

- £4bn was spent by the NHS on treating pressure ulcers in 2013. Not all of these pressure ulcers relate to wheelchair use, but it does play a part.
- As well as these additional healthcare costs, there is also a great amount of waste to our UK economy when we don't get it right. An estimated 450,000 wheelchair users are of working age and for every 182 wheelchair users not able to work, the benefits bill can increase by up to £1m. Whereas the positive economic contribution made when in work can be up to £4.7m.

Do you feel comfortable as a tax payer knowing this amount of money is being spent on treating problems, which could easily be avoided by smarter investment?

So why have we not been able to resolve this challenge?

Do we want to know?

Through the development of this digest we have evidenced some fantastic work across the system in relation to the provision of wheelchair services. We have also heard from wheelchair users about their lack of a voice in relation to the services they access, their frustration at not being listened to, not being able to influence their care and not being able to get the help they need when they need it. The NHS Constitution[3] sets out a series of commitments and rights to the people of England. These need to be made a reality for all wheelchair service users: if the NHS Constitution is not a reality for all wheelchair users we are letting people down.

As an older age psychiatrist I am delighted that dementia care is in the public eye at the moment: this is important and necessary and yet has taken many years to achieve. Like dementia, wheelchair services seem to emerge as a poor cousin to the more exciting medical issues that capture public interest and therefore rise to the top of our priority list.

Our tendency is to prioritise higher profile medical issues such as cancer and heart surgery when making decisions.

These issues garner lots of media attention and capture the imagination of the public, which creates pressure for change. Perhaps it is easier not to focus on the challenges faced by wheelchair users, who can become an unheard and unseen part of our community.

If the public were more aware of the situation I am sure they would feel as strongly as we do: change needs to happen and everyone can benefit. We need to find a way to raise awareness, capture the public's interest and garner their support to help us make a lasting change.

We don't always make it easy for committed people to do the right thing every time

We have heard from wheelchair users, staff and organisations that often the system works against committed people who keep trying to do the right thing. The complexity of the funding model doesn't help. People don't always know how to go about getting help and artificial boundaries make it hard when you are navigating across health, social care and the charitable sector, to secure what you need. You will hear some positive stories and some hard hitting stories in this eDigest. Hopefully you will ask the question: does it really need to be so difficult?

When we get it right, it is obvious what a difference we can make. I have been moved by the enthusiasm and commitment from across all sectors to pull together and take collective action now to put this situation right for everyone. I have also been humbled by the drive and determination of the service users and carers to work with us to improve the situation.

We have tried before: what will be different this time?

In the past our approach to improving wheelchair services has not resulted in better services for everyone, everywhere and every time. There have been impressive improvements in many areas and yet this has not spread. Where we see success, it is often because a whole system approach has been taken, rather than each bit of this complex system working in isolation to make improvements. If we recognise the challenge is a complex one then we think differently about the approach we need to take for a lasting change to wheelchair services.

We must also recognise the value of local solutions for local people, and this will mean different solutions will emerge, in different parts of the country: all delivering the same outcome.

We need a system wide, concerted effort: each part of the system doing what it can to help all parts be as effective as they can be, if we are to successfully reduce harm, unacceptable delays and waste.

We are delighted that NHS England is already working to change things: by improving the quality of the data and the way it is collected so the data influences what we do; piloting a tariff for wheelchair services and developing resources to support commissioners of wheelchair services. Alongside ensuring all the levers are in place to align the system where it is possible, we think there are other things that can be done:

- We should work across the system to create a wheelchair leadership alliance to bring representatives of all key stakeholder groups under one umbrella, to lead a collective effort in response to this challenge
- We need a campaign that raises the profile of this intolerable situation and that mobilises all involved with wheelchair services to work collectively to make a lasting positive change.
- We need a wheelchair 'constitution' that all services will sign up to. This would set out what good looks like, remind us of the rights people have and describes the commitments services will make for wheelchair users.

Ultimately we need everyone to commit to:

RIGHT CHAIR RIGHT TIME RIGHT NOW

Professor Moira Livingston
Clinical Director, NHS Improving Quality
@IQMoira @NHSIQ

BACKGROUND

Providing the most suitable wheelchair, at the most appropriate time is essential to the 1.2 million wheelchair users in England[5] who are unable to mobilise independently. When a wheelchair user has the right wheelchair they experience a greater sense of freedom and independence. They can play an active role in society, and have an improved quality of life.[6,7] Consistently high quality, wheelchair services provision is essential in enabling this to happen.

NHS wheelchair services are locally organised and offer assessments to determine what type of wheelchair or mobility equipment a person may be entitled to on the NHS and then prescribes equipment. Individuals should be assessed according to their physical, social and environmental needs.[8] Wheelchair services are available to people of all ages who have a long-term need for mobility help. However, there are local eligibility criteria that vary depending on where you live.

> **“Wheelchairs provide a significant gateway to... independence, promoting wellbeing and quality of life for thousands of adults and children.”**
>
> Out and About, 2006[4]

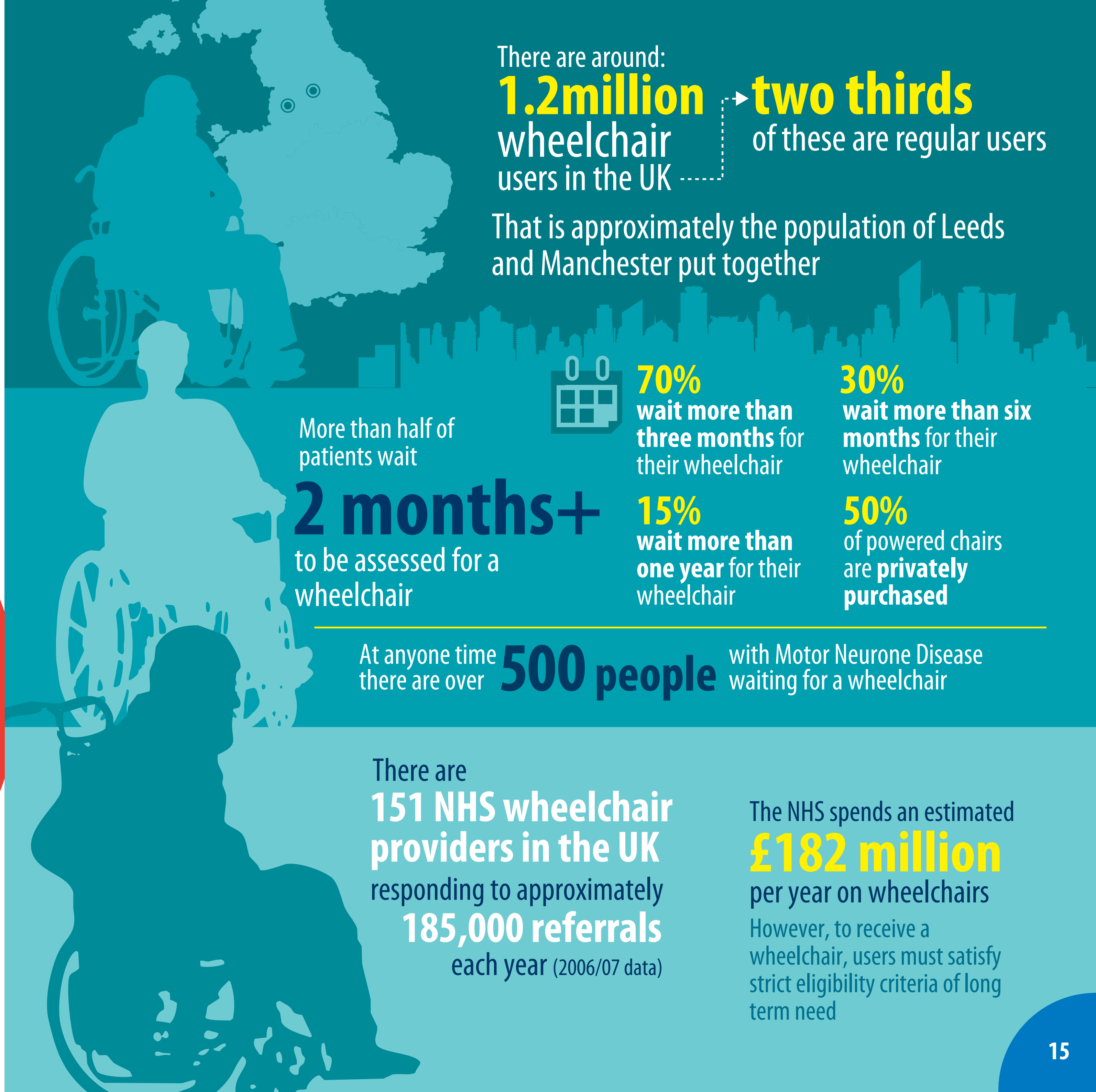
The voice of parents and users: Two mothers of wheelchair users and a wheelchair user discuss their experiences of wheelchair services.

People may be signposted to *access to work* or charities if it is deemed they do not meet the local eligibility criteria. Equipment is prescribed from the NHS range, but there is a voucher scheme that can contribute to the cost of a wheelchair outside of the NHS range. NHS wheelchair services are funded to maintain and repair the equipment and either sub-contract or run an in house repair and maintenance service.[9]

Over the last three decades there have been numerous reports, reviews and recommendations for change in relation to wheelchair services[10,11] from government, statutory and voluntary service sectors. There is a growing acknowledgement that there is considerable variation in wheelchair services and provision across England[12]. There is also a wealth of evidence that the experience of wheelchairs users and their family and carers whilst often good can also at times be shockingly poor.[13]

It was the recognition of this variation and the associated negative impact on people's lives which led NHS England to commit to supporting a fundamental change to wheelchair services in England as part of NHS Change Day 2014.

> **"...the most important thing for me is that every time my needs have changed, wheelchair services have responded and adapted my equipment to suit ..."**
>
> **Paula, wheelchair user**



There are around:
1.2million wheelchair users in the UK → **two thirds** of these are regular users

That is approximately the population of Leeds and Manchester put together

More than half of patients wait **2 months+** to be assessed for a wheelchair

70% **wait more than three months** for their wheelchair

30% **wait more than six months** for their wheelchair

15% **wait more than one year** for their wheelchair

50% of powered chairs are **privately purchased**

At anyone time there are over **500 people** with Motor Neurone Disease waiting for a wheelchair

There are **151 NHS wheelchair providers in the UK** responding to approximately **185,000 referrals** each year (2006/07 data)

The NHS spends an estimated **£182 million** per year on wheelchairs

However, to receive a wheelchair, users must satisfy strict eligibility criteria of long term need

Why are we committed to help?

From the research conversations, and evidence that we have gathered so far, we think more needs to be done. We need a fresh approach that recognises the improvement efforts made so far and the complex nature of the challenge. NHS Improving Quality acknowledges that there is notable practice in wheelchair services to build upon that will help us to remove the significant variation that currently exists. And we are keen to offer our extensive service improvement expertise to help those with an interest in wheelchair services to bring about the change needed; change that will help us to avoid harm, avoid unnecessary delays, reduce waste and create a much better experience of care for all people who rely on wheelchair services to maintain their freedom and independence.

Alongside this, complimentary work at NHS England, that aims to address some of the system and processes changes required to support these improvements, is well underway and it is this combination of approaches that leads us to conclude that together we can make a real difference this time.

The NHS England Change Day pledge "*to bring wheelchair users together with NHS clinicians and managers, and with third sector organisations, to improve services across England*" led to the first national wheelchair summit which took place on 25th February 2014. Key stakeholders gathered to consider the scale of the issue and to identify what they could do collectively to improve the situation. Attendees included service users; CCG commissioners, clinicians and senior managers; providers; colleagues from the third sector; social care and education and the Department of Health (DH) and NHS England.

As a direct result of the summit, commitments were made to address a number of system level issues related to wheelchair service provision. Six dedicated workstreams were created led by a cross section of key stakeholders with a special interest in wheelchair services. Their task is to focus on improving assessments, commissioning and procurement, integration between health and social care, the training of staff, the use of innovation and ensuring that wheelchair users and their family and carers are better informed and empowered.

SIX DEDICATED WORKSTREAMS

1. **Better assessment**
2. **Better informed and empowered service users**
3. **Better commissioning and procurement**
4. **Better integration of health and social care**
5. **Better training of staff**
6. **Better use of innovation**

Separately, NHS England has committed to working on the following priority areas:

1) The development of a national data set for wheelchair services
2) The piloting of a tariff for wheelchair services
3) The development of resources to support commissioners of wheelchair services.

However addressing system levers alone is unlikely to bring about the transformational change needed in wheelchair services. As such NHS Improving Quality is supporting the work of the summit through three strands of work:

1) To look at the evidence and information about wheelchair services in order to provide a baseline of existing wheelchair service provision in the form of an eDigest
2) To support further development of the summits work through co-design and delivery of a second summit
3) To co-design and lead the launch of a campaign aimed at mobilising all those engaged in wheelchair services in order to bring about transformational and sustainable positive change.

This eDigest then represents a review of literature in relation to wheelchair services in order to provide a baseline of current provision and has also been informed through direct engagement with service users and providers.

Its aim is to pull together the evidence base presented within the summit's *The NHS Wheelchair Service. The Case for Change* (2014) paper[14], current intelligence from the six activity workstreams, and to carry out an in-depth review of the wider literature, in order to answer the question,

"Do we have an intolerable situation with wheelchair services? What does the evidence base tell us about the current state of wheelchair services in England, in relation to people with complex and changing needs, and its impact upon people's lives and health, care and voluntary services?"

The eDigest considers what else the evidence base suggests might be done differently to address recognised service deficiencies and will serve to underpin the subsequent call to action campaign and its associated activities. It also highlights the numerous examples of innovative practice and improvement work that are already happening across the country, to address some of the known deficits, to ensure that wheelchair users are getting a good experience of care.

The term 'complex and changing needs' used within this eDigest is defined as 'daily wheelchair users, of all ages, who have changing and/or multi-faceted health and care needs'. Why have we chosen this group? We think that by focussing on services for this group we are more likely to get it right for everyone.

As we have scanned the evidence we have come across information on areas such as funding levels, eligibility criteria and unmet need which were out of scope of this work. We therefore have not included recommendations in these areas.

In compiling this eDigest over 600 academic abstracts have been reviewed for relevance, 60 documents have been reviewed in detail and material has been reviewed from over 30 key stakeholder organisations and individuals across the statutory, voluntary, commissioning, provider and academic landscape.

Intelligence has been incorporated from the first national wheelchair summit and the summit workstreams where available. There has been a review of relevant content from Twitter in the last 12 months and consideration of 11 wheelchair service user reviews from www.patientopinion.org.uk and www.iwantgreatcare.org

Additional evidence has also been provided from a series of qualitative interviews undertaken by NHS Improving Quality with individuals with a close affinity to wheelchair services.

WHY DO WE NEED TO ACT?

It has been suggested by numerous reports into wheelchair services and by user feedback that there is an intolerable situation for those who need a wheelchair in England. To explore whether this situation exists we have reviewed as much evidence as we can find to see if this is actually the case.

This is what the evidence is telling us…

Choice – An overview

The Posture and Mobility Group research[15] in 2014 explored user choice in relation to the provision of equipment to wheelchair users. Around 30 wheelchair users from across England took part. The findings showed that choice was often limited. Users perceived they had little or no choice when it came to wheelchair and postural seating services and this was often linked to a lack of information on the voucher scheme or the chairs and equipment available.

There was also a clear lack of awareness and understanding around the Any Qualified Provider (AQP) model.

Users stated that they want equipment decisions made on a social rather than a medical model of disability, to take account of all of their needs. This was often felt not to be the case.

Poor quality chairs and equipment were reportedly issued (with regular repairs required but not dealt with in a timely manner) leaving some users without any chair provision for several weeks. And there was often confusion around who meets the cost of repairs.

There was little criticism of Wheelchair and Postural Seating (WPS) service staff, who were described as trying to do their best whilst constrained by central policy and budgets.

The current approach to wheelchair and posture services provision was heavily criticised as being short sighted and cost ineffective. ‘Money saving’ approaches were perceived to be costing the service more in the long run because of the need for additional health and social care services to manage the impact of secondary complications. There was also recognition of an increased reliance on welfare benefits where peoples’ ability to be active in the labour market was also affected by the lack of the correct chair.

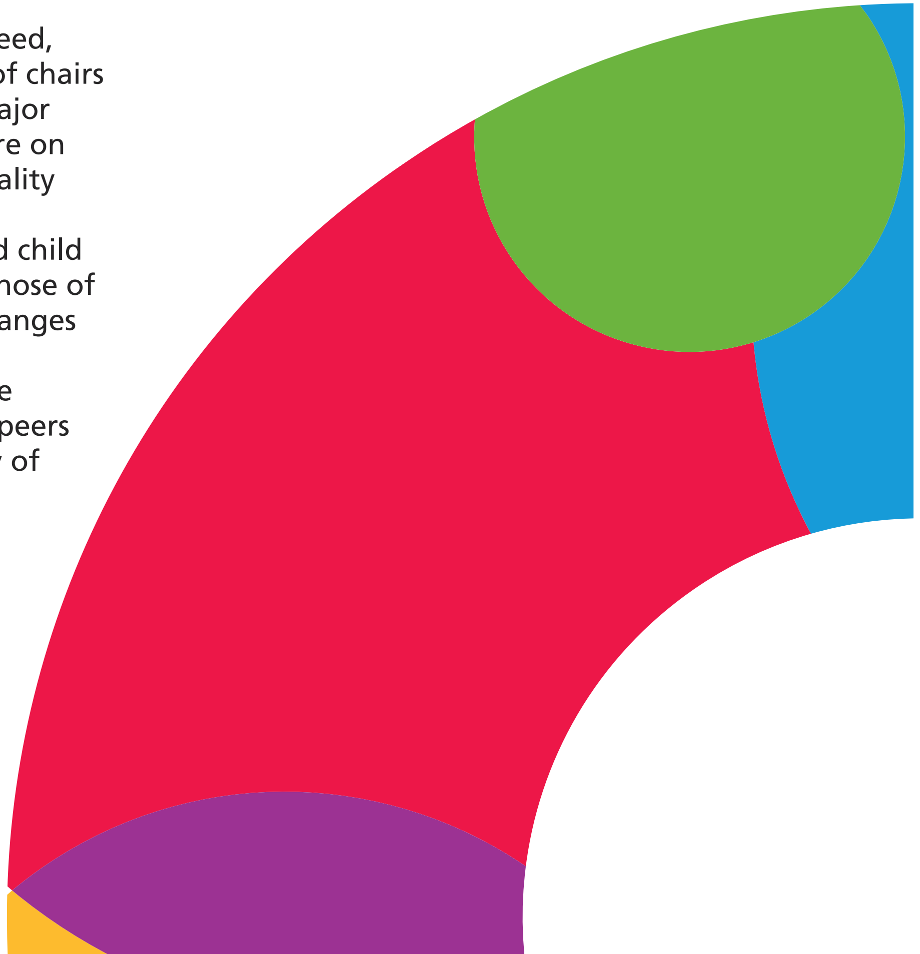
The voice of parents and carers: **Two mothers of wheelchair users discuss their experiences of wheelchair services.**

> **“Staff listened and got it… I now have a new powered wheelchair. Nothing special? Not normally, but they took the time to understand me and my needs, to make sure I would get the chair that was right for me. And I have![19]”**
>
> **Wheelchair user talking about Bromley Healthcare/ Wheelchair and Special Seating www.patientopinion.org.uk**

To improve ‘choice’ in wheelchair and posture services, users want:

- A more holistic approach to meeting users’ needs
- Better provision of information to users on the products on the market that would be suitable for them, and more information on the Voucher Scheme
- Separation of the assessment of need, from procurement and provision of chairs and equipment; the DH, as the major purchaser, to place greater pressure on manufacturers to provide high quality equipment at an affordable price
- Recognition that young adults and child users’ needs often differed from those of other users given rapid growth changes etc: alongside recognition that all wheelchair users are no less ‘image conscious’ than their able-bodied peers
- To address the current inadequacy of repairs and maintenance services

This review has identified that many of these concerns were highlighted and have been recognised by the wheelchair summit and they are now being addressed through the ongoing work of the six summit workstreams and through the prioritised system levers work being led by NHS England.



Are wheelchair users and their families and carers getting a solution that meets their health and care needs?

The evidence suggests that whilst sometimes things do go smoothly for those needing a wheelchair, all too often this is not the case.

At a local level during 2012/13, the NHS Clinical Commissioning Groups (CCGs) of Calderdale, Greater Huddersfield and North Kirklees had concerns about the wheelchair services provided to their local populations. Services were overstretched and overspent each year, with the reasons for overspending being unclear. One-off amounts of money have been put into supporting the service over the last few years as demand has exceeded the capacity of the service. The CCGs commissioned NHS West and South Yorkshire & Bassetlaw Commissioning Support Unit (WSYBCSU)[17] to review the service.

Engagement with wheelchair users, carers, Healthwatch, social care staff and disability workers identified some of the following issues:

- Unacceptable waiting times for assessment and repairs
- Need for training on the progressive nature of some conditions
- Need for customer service training
- Need for consistently applied eligibility criteria
- Need for an out of hours service
- A need for additional resources (including therapists and technical support)
- Poor communication between the service and service users
- Choice of equipment being limited by cost rather than suitability.

> **“We are not asking to fly to the moon, just to do the things other people take for granted.”**
>
> Out and About,
> 2006

These issues are now being addressed locally, as described further in the innovative practice examples given later in this eDigest, to ensure that wheelchair users and their families and carers will get a solution that meets their health and care needs.

At a national level stakeholders gathered at the NHS England Wheelchair Summit in 2014 to consider the issue of wheelchair services and what more could be done to improve people's experience of engaging with wheelchair services.

Stakeholders from the wheelchair summit described some of their experiences and thoughts.

- The process (of getting a wheelchair) needs clarity and consistency across the country
- Wheelchair services eligibility criteria do not promote independence and create artificial choices
- Wheelchairs offered should meet people's holistic needs – people should not have to buy their own
- We need systematic, honest assessment of individual needs
- Better and more cost effective decisions could be made if based on current and future needs
- Services should prioritise pain reduction and independency.

Our review of the evidence has found that these are all common themes and that there are many areas in wheelchair service provision where we could do better.

They include:

Variation in services

Whilst online reviews from wheelchair service users identified some really positive experiences this was not consistently the case.

Of these reviews, a quarter praised the wheelchair services they had been in contact with.

Of the less positive experiences, the most common issue raised was the wheelchair offered by the NHS did not meet the person's needs, and the assessment did not take a holistic approach to establishing those needs.

Other issues included overly strict eligibility criteria for specific wheelchair or associated equipment, and vouchers offered by the NHS not covering the full cost of the wheelchair.

The voice of a wheelchair user:
A wheelchair user discusses her experiences of wheelchair services.

> **I think it would do everybody good to spend a day in a wheelchair to know how difficult it is to get around. In simple terms to get up and down a curb, to cross a road, to do anything. It's really difficult and if people knew how hard it was they would vastly improve the services out there in lots of respects.**
>
> Eileen, mother of Nathan,
> a wheelchair user

> **Wide variation in assessment, service delivery and quality of provision characterises wheelchair services.** [20]

Out and About in 2006,[21] went on to state that *"The huge variation in service structure and skill mix leads to equally significant variation in levels of service provision and service quality."* More recent sources indicate little has changed in the intervening period.

In 2008, a review of National Wheelchair Services found, *"assessment, procurement and delivery approaches differed considerably, leading to significant inefficiencies and a poor record of service delivery nationally."*[22]

The voice of a wheelchair user:
A wheelchair user discusses his experiences of wheelchair services.

> **Wheely good service at the mobility rehab centre!... As someone with a neuromuscular condition whose life depends on the use of a chair suited to their condition this was such a great experience. I do hope the services elsewhere in the country are of a similar high standard. Brings a whole new meaning to the word 'quickie'!**

About Primary and Community Services/
Sheffield Mobility & Specialised Rehab Centre
https://www.patientopinion.org.uk
(posted Sept 2014)

In 2014, many service users interviewed ahead of the NHS England Wheelchair Summit felt it impossible to rate wheelchair services as they were simply too variable.[23]

NHS benchmarking data also indicates that there is variation in services. For example, waiting times in 2014 ranged from 9 days to 256 days (average 33 days) across 13 services who participated. In 2013 waiting times ranged from 4 to 96 days (average 42 days) across 24 services.[24]

> **Even though I could still not walk and had weak arm muscles, I was told that I only qualified for a manual wheelchair. I then asked whether I could add the powered wheels and was told that as it was the property of wheelchair services I could not. After three months of letters and phone calls they finally agreed that I could - so I bought them (it cost me £3,700) but it was worth it as it means I have more independence when going outdoors as I can push myself where I want to.** [25]

The Muscular Dystrophy Campaign report Get Moving (2013)[26] highlights that *"The Government itself in 2007 noted that 'provision may focus too heavily on clinical need and fail to take into account the impact of independent mobility on social, development and educational attainment, or on family's preference'."*

Further reports expressed that the wheelchair users' individual needs were not always considered. Sometimes clients felt that they were not listened to or given the opportunity to express their needs in respect of their lifestyle. There was a general feeling that the service was equipment and process focused rather than people's needs focused.[27] Others have indicated that choice may all too often be limited by budget rather than clinical need, with the criteria being used as a gatekeeping mechanism.[28]

Recognising this, Workstream 1, *Better Assessment* from the Wheelchair Summit is working on the development of a 'gold standard' for commissioners for prescription assessments. The group is also engaging with manufacturers to ensure quicker lead in times, improved delivery, stocks and costs.

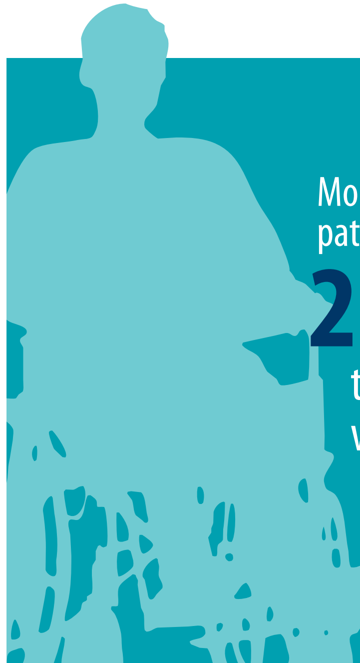
The voice of a healthcare professional:
A healthcare professional discusses her experiences of wheelchair services.

Lack of timely provision

Long delays are a common issue. A service review in Portsmouth found that the greatest dissatisfaction was attributed to delays and waiting times, with a particular focus on unresponsive and insufficient repair and maintenance services.[29] These issues were also raised at the NHS England Wheelchair Summit, February 2014.[30]

Get Moving (2010)[31] states that the Department of Health document, Healthcare Standards for Wheelchair Services, outlines a range of minimum response times for certain stages of the process but that it *"sets no benchmark for waiting times for the entire process from initial referral to the delivery of the chair. It is clear that if a target for waiting times for wheelchairs does exist there is a great deal of confusion around it and these targets are not being met."*

There is a wealth of evidence of the impact of the lack of timely provision of wheelchair equipment in both the literature and the personal experiences that we reviewed and these are described in more detail throughout this eDigest and within the *Impact of Delays* section.



More than half of patients wait **2 months+** to be assessed for a wheelchair

70% **wait more than three months** for their wheelchair

30% **wait more than six months** for their wheelchair

15% **wait more than one year** for their wheelchair

50% of powered chairs are **privately purchased**

At anyone time there are over **500 people** with Motor Neurone Disease waiting for a wheelchair

In summary these delays can result in harm (through the development of complications such as pressure ulcers, contractures or mental health issues), waste (as a result of the costs of having to treat these complications over, sometimes, prolonged periods of time) and a poor experience of care for the person and their family and carers who are reliant on their wheelchair for their independence and freedom.

The holistic needs of children and people with specific conditions are not being met

The evidence base suggests that there may be specific issues for those with muscular dystrophy and related neuromuscular conditions where their holistic wheelchair needs are not adequately assessed.

Three years after reporting that the standard of care provided by NHS Wheelchair Services was simply not acceptable for people with muscle disease and their families, the Muscular Dystrophy Campaign; Get Moving , highlights that there has been little improvement.

The voice of a parent and carer:

A mother & carer of a wheelchair user discusses her experiences of wheelchair services.

It reported in 2013 that:

- Assessments are insufficient and don't take account of the varying needs of individuals and their lifestyles
- Generic manual wheelchairs were often inappropriately provided for people with muscle-wasting conditions
- Almost half of respondents that use a wheelchair did not receive full NHS funding for its cost, and they are forced to turn to alternative sources to top up or fully pay for their wheelchair
- Approximately one-third of patients waited more than six months after requesting an appointment from the NHS to receiving the wheelchair
- Over one-third of respondents have to fund the upkeep of their wheelchair themselves
- There are often long waiting lists for repairs and charities are often relied upon for help

Similar issues were identified by the Newlife Foundation[33] in 2012 in relation to disabled and terminally ill children. The Newlife Foundation reported that disabled and terminally ill children were not getting the equipment (including wheelchairs) that they needed. The impact of this was so severe on children and their families that the foundation developed its own emergency equipment service as described in more detail later in this eDigest.

> **“If we cannot supply the basic equipment they (disabled and terminally ill children) need, what does that say about our society?”**
>
> **Mrs Sheila Brown**
> **O.B.E, FRSM, CEO**
> **Newlife Foundation for**
> **Disabled Children**

Charities filling the void of unmet need

The Newlife Foundation[34] report highlighted repeatedly the dedication and hard work of health and care staff, but stated that they were working within a bureaucratic system that prevented professionals achieving the desired aims and objectives for the people using their services. Over seventy five percent of NHS staff who help families apply to the Newlife Foundation for equipment have reportedly not applied to statutory services first as they don't see any point in doing so (the reasons given including lack of funding, rationing of equipment, leaving families to cover some of the cost, pressure to downgrade assessments and an inability to provide equipment quickly enough).

In an earlier report[35], Newlife Foundation highlighted, "*a scandalously poor and worsening system of equipment provision by local statutory services,*" and claimed that charities were, "*filling the void created by inadequate statutory provision*".

This report stated that just 14 charities had funded a quarter of the total amount spent by all statutory services during 2005/6.

An estimated
450,000
wheelchair users
are of working age

The average reduction in benefits per disabled person securing paid employment is
£5,495
annually

A previously economically inactive individual securing work generates an additional
£25,700
of economic output

Up to
100,000 users
will develop pressure ulcers from being given the wrong chair

Up to **50%**
of wheelchair users
will develop a pressure ulcer at some point during their life

Wheelchair users
who develop pressure ulcers often spend **30%** of their time being treated

A full thickness sacral sore costs as much to treat as
16 hip replacements

The forgotten needs of carers

The evidence review suggests that it isn't just the needs of wheelchair users that often aren't being met. A research study by PAMIS investigating the needs of carers[36] stated that, "*It is of concern however that the needs of carers who manage wheelchairs are not mentioned in any of the key policy documents referenced… nor is the potential impact on their health*".

The results of this study by PAMIS evidenced negative carer impacts such as increased pain, and a lack of assessment of their needs as a carer, as part of the overall wheelchair assessment "*76% did not think that their health needs in particular had been taken into account*". For example issues included lack of training to manage the wheelchair, environmental issues in the home, and potentially being placed at risk through exceeding safe load management guidelines.

Lack of progress, despite the best efforts

In its summary, the Newlife Foundation[38] concluded in 2012 that despite a number of initiatives introduced since 2007[39] in relation to some of the issues outlined here, the issues persist. For example, the Care Quality Commission (CQC) report "*Health Care for Disabled Children and Young People*" (2012)[40] revealed that in a third of PCTs, children waited between 11 and 50 weeks for wheelchairs.

> **"New findings reveal that there are still substantial gaps in specialist wheelchair provision for people with muscular dystrophy and related neuromuscular conditions. Improvements are urgently required, at both a national and a local level.[37]"**
>
> **Muscular Dystrophy**
> **Get Moving Campaign**
> **2013 - Patient Survey Findings**

The voice of a parent and carer:
A mother and carer of a wheelchair user discusses her experiences of wheelchair services.

In 2009, the Department of Health launched a new programme of work to refine the proposals set out in *Local Innovations in Wheelchair and Seating Services*[41] in partnership with the NHS, service users and other stakeholders. The aim was to develop a commissioning approach that would facilitate timely provision of wheelchair and seating services focused on the health, social and lifestyle needs of the service user. [42]

However the NHS Benchmarking Network's[43] findings, on average waiting times, support this growing concern about the variation in waiting times across the country. Their figures also show that waiting times have improved from 2013 to 2014; with median waiting times decreasing from 42 to 33 days. As only 13 services participated in this benchmarking exercise in 2014 compared to 24 services in 2013 direct comparison between these figures is difficult.

The Get Moving[44] campaign was launched in 2010, but a revisit in 2013 stated that many of the issues raised originally remain unaddressed. This is a view supported by many of the other documents referenced in this eDigest.

An overview of existing research found general agreement across models of wheeled mobility and seating service delivery but little high quality evidence to support recommended approaches and few studies of the relationship between service delivery steps and individual patient outcomes. All stakeholders (i.e. clinicians, rehabilitation technology suppliers, manufacturers, researchers, payers, policy makers, and wheelchair users) need to work together to develop and support an evidence base for wheeled mobility and seating service delivery.[45]

WHAT HAPPENS WHEN WE LET PEOPLE DOWN?

This quote (highlighted on the right) from a wheelchair user shows just how essential an appropriate wheelchair is. It is not simply a piece of medical equipment, but is often essential to all aspects of a person's life. So, what happens to people when we let them down and they don't get the wheelchair they need, when they need it?

Wheelchair users at the NHS England Summit in February 2014 were clear about the impact a poor service has on them.

Here are some examples:

"A wheelchair is your legs, if it's broken and not maintained it can leave you stranded and isolated for weeks"

"Having to wait three months for a chair is not okay"

"A chair for today may not be right for tomorrow"

> **"My wheelchair is my life - without it I would not have a life... my chair goes a long way to making my life manageable, keeping me sane and sociable."**
> Out and About, 2006[46]

"Some of the so called smaller problems really matter – like your hands getting sore from propelling your chair."

"Without the right cushion, you can get ulcers and broken skin – it's not pleasant"

We have reviewed the research to try to understand the impact on people and their families and carers when we let them down with their wheelchair services. This is what we have found:

Impact of not meeting individuals' holistic wheelchair needs

Scott (1981) suggests that access to the correct powered wheelchair significantly improves mobility, prevents deformity and reduces pain and discomfort. Davies (2003) suggests that access to the right equipment reduces the risk of developing complications including scoliosis and contractures, and that the need for extended hospital stays and expensive treatment is further decreased. He also suggests that there is a correlation between the benefits of good equipment and quality of life.

Prescribing a wheelchair is a complex therapy intervention. The experience of wheelchair users and organisations that fund equipment confirm that a wheelchair which is poorly matched to the individuals needs adversely effects the user's activities and participation, lifestyle goals and health status, as well as adding to cost and more often resulting in non-use or abandonment of the prescribed wheelchair.[47] Despite this the experience of many wheelchair users is that often there are long delays for wheelchair provision and that the chair provided does not always meet their holistic needs.[48]

The voice of a wheelchair user:
A wheelchair users discusses her experiences of wheelchair services.

The literature highlights other factors that lead to non-use or abandonment of wheelchair and poor match to individual need, including:

- limitations in assessment and intervention support
- limited client participation in the prescription process
- issues around personal device related factors
- limitations in consideration of environmental factors[49]

Delays in providing an appropriate wheelchair can result in: an especially detrimental impact on the quality of life for people with muscle-wasting conditions: increases the possibility of unplanned emergency admissions to hospital:[50] unintended harm for the individual and increased cost to health and care services.

> **"For many people with a neuromuscular condition a powered wheelchair is vital for independence and quality of life, and is also essential to help manage any physical complications. Access to the right equipment at the right time can also help to slow the progression of the condition and improve prognosis..[51] "**

The evidence shows generic manual wheelchairs are often provided for people with muscle-wasting conditions. But inadequate seating can exacerbate scoliosis and contractures and lead to the development of pressure ulcers. This highlights the crucial importance of customising powered wheelchairs for many people with muscle-wasting conditions, including the use of supportive seating and tilt in space wheelchairs. The provision of the correct chair can potentially reduce the cost to the NHS in the long run by avoiding the need for corrective surgery and costly stays in hospital.[52]

Impact on children with disabilities including terminally ill children

Research in education[53] shows a number of impacts on the experience of children in wheelchairs:

- Problems with adapting the built school environment are still leading to discriminatory practices such as when children have to use the kitchen entrance to get into the school
- Disabled children and their families have limited choices when it comes to choosing schools
- The issue of wider social inclusion in schools has yet to be fully addressed with many disabled children and young people unable to eat lunch and join in at break times with their classmates
- Attitudes to inclusion vary from school to school. Some schools are better than others.

Whilst most of these issues are environmental, cultural and societal (and so outside of the scope of this eDigest) it was felt by that early provision of an appropriate wheelchair would help support a child's educational experience, but families face unacceptable challenges in accessing the right mobility equipment and wheelchair assessment does not take into account the varied activities which are part of life in a mainstream school.[54]

The findings were endorsed by other organisations in supporting letters. They included:

- **Barnardo's Cymru** referencing the similarities in findings to their joint report with Whizz-Kidz
- **Children in Wales** who reference the similarity to their findings in a report published in 2002
- *Family Fund* who validate the findings based on their engagement with multiple families seeking financial assistance for wheelchairs and buggies
- **Whizz-Kidz** who give additional endorsement and recommendations for improvement.

The Newlife Foundation also describes the impact that delays in providing necessary equipment has on disabled and terminally ill children and their families, in terms of children suffering pain and distress. In their 2012 report into wheelchair service provision the Foundations' regular engagement with family's revealed significant issues regarding the timely provision of equipment and to help address this they felt compelled to launch their own emergency service. "*Last year Newlife had to launch a nationwide emergency service to supply urgently-needed equipment to terminally ill children. Things were so bad that not even dying children were receiving the equipment they needed*[55]."

Impact of delays on all

The provision of specialist chairs for those people with specific conditions are often not provided in time to avoid devastating physical consequences and yet it is widely acknowledged that the provision of the right equipment at the right time is essential to help improve prognosis and to slow condition progression. The Muscular Dystrophy Campaigns' report *Getting Moving* (2010)[56] report that timely provision of equipment helps to reduce the risk of secondary complications significantly benefitting the individuals, and their carers, quality of life and reducing the cost burden on health and care services.

Despite this numerous reports have evidenced significant delays in the timely provision of wheelchairs regardless of the age or diagnosis of the person requiring a wheelchair. The CQC report '*Health Care for Disabled Children and Young People*', reporting "that some disabled children have to wait up to a year to get essential equipment". And they go on to note that, "*Long delays can have a detrimental effect on the child's wellbeing.*[57]"

Impact on carers

The Keeping the Wheels Turning[58] report highlights the issue of an ageing population of unpaid carers, the majority of whom were supporting someone who uses a manual wheelchair.

Just over a quarter of the carers in this study reported additional health needs themselves, such as breathing problems, heart problems and/or issues with balance, which caused extra difficulties in their caring role.

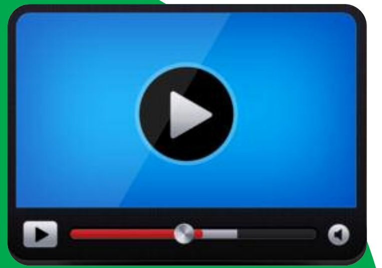
A second report by Stewart and Paterson (2010) highlighted national figures for carers: 18% of carers caring for over 20 hours a week report poor health. This research aimed to record carers' needs in relation to wheelchair management.

These findings raise serious concerns about the health and wellbeing of carers who look after a wheelchair user and current arrangements for targeted carer identification and assessment. The key impacts can be seen in the infographic on the right:

Impact on costs

It is hard to quantify the cost of getting wheelchair provision wrong, in terms of cost to the health service, to social care and to the wider economy. Similarly, it is potentially easy to underestimate the value in getting these services right.

The voice of a parent and carer:
A mother and carer of a wheelchair user discusses her experiences of wheelchair services.



The New Life Foundation reported that carers saw no point in first applying for help from statutory services

Parents are regularly left to find
85% +
of the costs for a powered chair for their child

An estimated
450,000 wheelchair users
are of working age

Every 182 wheelchair users

not able to work potentially increase the benefits bill by up to **£1 million**

Whereas if in work they create up to **£4.7 million economic benefit**

75% of carers
experienced difficulties with wheelchair management particularly through lack of training

Unpaid carers
in the UK contribute an estimated
£15,260 pa
in terms of the economic value of the care they provide

Shoulder pain was
4 x higher
in carers propelling manual compared to powered chairs

76% of carers
did not think their health needs had been taken in to account during wheelchair assessment

Carers are often vulnerable themselves
22% of carers are aged 65+
3.1% of carers are children

72% of carers
of wheelchair users report back pain &
48% report shoulder pain

Most of the evidence considering cost looked at the overall impact of disability as opposed to specifically focusing on wheelchair users. However the evidence did acknowledge that wheelchair users often had lower levels of access to educational and employment opportunities.

Due to the multiple barriers facing people with disabilities the evidence could not confirm that improvements in wheelchair services would result in improved employment opportunities. However it is possible that such improvements would at least help to remove a potential barrier to employment.

Similarly, it is possible that wheelchair services that take account of a child's holistic needs would reduce the need for assistance in schools and any associated costs. However the evidence did not manage to robustly quantify these potential savings.

The effect of improving wheelchair services on NHS expenditure was also unclear. Whiz Kids suggested that between 1 to 5% of the total return on investment from improving wheelchair services could relate to reduced healthcare costs.[59] The bulk of return on investment linked to improved wheelchair services was attributed to the wider social and economic impact of these changes such as reduced social care costs and increased economic activity. An internal report[60] also suggests that actions to improve wheelchair services may actually increase healthcare costs under some circumstances.

The case for improvements to wheelchair services is strongly supported by the impact the improvements are likely to have on wheelchair users and their carer's quality of life. There also appears to very rational arguments to support the potential for increased economic activity of wheelchair users and carers and reductions in associated social care cost as a result of these changes. Detailed analysis of the cost impact of inadequate wheelchair services can be found within the comprehensive wheelchair Summit, 2014 *Case for Change* paper.[61]

WHAT DOES IT LOOK LIKE WHEN WE GET IT RIGHT?

This eDigest highlights that there are significant variations in the quality of wheelchair provision across the NHS. And whilst there are areas of very good practice this variation all too often means that the needs of individuals are not met, sometimes with devastating consequences. In order to tackle variation, we need to share and spread examples of good practice and the learning from service improvement activity as it occurs.

Recognising this, Workstream 6 of the Wheelchair Summit is working on creating an NHS innovation portal to promote innovation in wheelchair services through user generated content. They plan to launch this at the next wheelchair summit on the 27 November 2014. The portal content will include case studies, wheelchair innovation ideas, best practice and more and may give 'awards' for great innovation. In the meantime the review of the evidence has also found that there are many existing examples of good practice in NHS wheelchair services, and other supporting tools such as standards and outcome measures.

> **"...manufacturers need to look at making them [wheelchairs] smaller, making them lighter, making them have a smaller footprint and they also need to look at incorporating technology into them..."**
>
> Mark Stone,
> wheelchair user

In order to tackle variation, it is especially important to identify, share and spread these examples and tools to enable learning and service improvement to occur widely.

The voice of a wheelchair user: A wheelchair user discusses his experiences of wheelchair services.

Listen to wheelchair users, their families and carers, and to professionals

Delegates at the NHS England Wheelchair Summit in February 2014 suggested the following improvements for wheelchair services:

SERVICE USER REQUIREMENTS

- Understand the person's needs and lifestyle and be realistic
- Transitions from child to adult services: standardisation should enable lifestyle to be maintained
- Service users to be able to give feedback and be involved in evaluation PROMS?
- Involve the service users in wheelchair design and delivery
- Reduce waiting times by improving the supply chain - provision and repairs
- After care - follow up - renewal of equipment once provided
- Support independence by asking how the service user wants to live and what their goals are
- Repair teams should be mobile and able to visit service user to repair chairs
- Can we try before we buy?

SOME SUGGESTIONS FOR IMPROVING SERVICES

- **Proactive maintenance rather than waiting for the chair to go wrong. Review requirement to be checked via text**
- **Consider the long term needs and develop chairs that can be adapted as things change**
- **Wheelchair provision should be considered in every JSNA, HWB strategy and CCG plan**
- **There needs to be integrated health and social care needs assessment**
- **Improve training so MDTs can offer advice and recommendations about equipment**
- **Create 'wheelchair passports', how to use transport and even basic adjustments**
- **Explore how personal health budgets can be used for wheelchairs & mechanisms to support self-funded upgrades**
- **Replace silo funding with whole of life funding across health, social care and education**
- **Work with manufacturers to reduce costs, improve adaptability of chairs**

In response to this the Wheelchair Summit has initiated a number of work streams to start tackling some of these long standing issues.

For example the Wheelchair Summit Innovation Workstream has worked with *Whizzkidz* and *I Want Great Care* to set up a TripAdviser style review site for wheelchair services, see www.iwantgreatcare.org/search

This was launched in late September 2014, and gives wheelchair users a voice to raise concerns or commend the service they have received. It has also worked with WhizzKidz and *Mums.net* to set up a parents network; a forum for parents to talk and share information, experiences and provide informal support. See www.whizz-kidz.org.uk/get-our-help/parents-network

These initiatives are important because the evidence suggests that when people feel informed, they are more likely to be satisfied with the assistive technology (AT, which includes wheelchairs) and keep it.[62]

In recognition of this Workstream 2 of the Wheelchair Summit is also working on an information pack for wheelchair users and their carers about what they should expect from NHS wheelchair services. This information pack could also potentially act as an aid to interaction as sometimes wheelchair service users feel unable to raise issues or make a complaint. It will also set out the criteria for provision of specific equipment. In addition this group is exploring a possible alliance of national charities that work to maintain the profile of this service area.

Standards and guidelines

There are a number of standards, guidelines and sets of guidance that can help to drive improvements in the quality of services. The evidence base suggests that taking advantage of the best of these standards and guidelines could help variation to be managed out of wheelchair services. Examples of applicable standards and guidelines include:

- NHS Constitution for England (2014)[63] that sets out what rights and pledges people can expect
- Healthcare standards for NHS commissioned wheelchair services (2010)[64]
- Clinical guidelines for the prescription of a seated wheelchair or mobility scooter for people with traumatic brain injury or spinal cord injury (Australian Occupational Therapy Journal, 2013)[65]
- Operational guidance to the NHS – Extending patient choice of provider (2011)[66]
- Advanced Prescribing for Patients with a rapidly progressive condition (MND) Leeds Teaching Hospital (2013)[67].

Listening to the recommendations of others

Previous reports from groups such as the Newlife Foundation (2012), the Muscular Dystrophy Campaign (2010 & 2013), Out and About Wheelchairs (2006) and Keeping the Wheels Turning (2011), have made a number of recommendations for radical improvements to wheelchair services, and the evidence suggests that these recommendations are still relevant and have not all been acted upon.

Recommendations have identified the need for:

- Uniform eligibility criteria and service specification (to be developed with users and carers)
- Funding to be based on need, rather than budget driving clinical decision making (including ring fenced budgets for specialist wheelchairs)
- Transparency in policies and decision making
- Identifying efficiencies in the system (e.g. recycling equipment, reduce bureaucracy)
- Testing new service delivery models, including joint commissioning and whole systems working
- National strategic focus to improve access
- Setting out clear response times, and agreeing a target for waiting times
- The need for transparent and accurate data needed relating to demand (including the need for further assessment of the scale of any unmet need)
- The NHS to cover maintenance costs, even for privately purchased wheelchairs

In addition, Service delivery systems for assistive technology in Europe: an AAATE/EASTIN position paper, makes nearly 100 recommendations for how assistive technology (including wheelchairs) could be improved across Europe.[68]

Outcome measures

Greer and colleagues' published review, highlights the lack of standardisation in the way in which services are delivered, and a lack of research evaluating delivery approaches. Seating and mobility experts generally agree on how wheeled mobility service delivery should work. However relatively little is known about how delivery processes work in practice or their impact on patient outcomes including activity, participation and impact of the service delivery on quality of life.[69,70]

A number of outcome measure tools are available. For example:[71]

- Wheelchair Outcome Measure (WhOM);
- Functioning Everyday with a Wheelchair (FEW)
- Goal Attainment Scaling
- Psychosocial Impact of Assistive Devices Scales
- The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST).

Research suggests, however, that no single outcome measure captures all necessary information; trade-offs are inevitable. When choosing an outcome measure, the specific goals of the service evaluation and the resources available need to be considered within context.

Recent and emerging innovative practice examples

The evidence suggests that there is no one ‘perfect’ system, it’s not a ‘one size fits all’ approach that is needed, far from it in fact. There are lots of things that are done really well that we can all learn from.
What follows is not an exhaustive list of innovations in, or for, wheelchair services by any means, they are just some of the examples of innovative practice we have come across in the course of developing this eDigest. Notable practice needs to be highlighted and celebrated much more widely in order to help tackle unacceptable variation.

Local innovations in wheelchair and seating services (2010)[72] aims to support commissioners and local wheelchair service managers by capturing current examples of local innovations that improve quality in wheelchair commissioning and delivery. It presents 12 case studies covering a range of issues.

Whizz Kidz (for children and young people, but also as a partner to the NHS in the provision of wheelchair services to adults). Has adopted a holistic approach to assessment, which begins before the first assessment, and made improvements to the stock management and supply side of the process. As a result Whizz Kidz state that they have:

- Improved outcomes for **Adults in Tower Hamlets** by more than halving waiting times, and offering a wider choice of equipment. They have achieved cost savings through negotiating better deals with manufacturers. They have seen a 16% reduction in service costs, have demonstrated improved quality of life for longer for the wheelchair user and have achieved 100% satisfaction for service users.

- **For children in Tower Hamlets** achieved improved quality of life and 60% saving per user cost and 55% saving in the cost per wheelchair (£1,100 compared to £2,500 under ‘business as usual’).

Neurological Commissioning Support (NCS) harnessed voluntary sector expertise to make a real difference, especially with more complex long term conditions. By working with patient experts NCS was able to show commissioners and service providers in Gloucestershire the problems that people with motor neurone disease (MND) were facing when using wheelchair services, because of how quickly their condition can progress.

This resulted in a more streamlined wheelchair referral process, specifically for MND patients. As a result wheelchair assessment waiting times have dramatically improved from eight weeks to 2.8 weeks and wheelchair services make MND patient referrals a high priority. Patients report that the service has improved markedly.[74]

Yorkshire and Humber Improvement Academy & Yorkshire and Humber Wheelchair Services[75] carried out wheelchair service improvement work in 2013 and 2014. This included work to improve relationships with commissioners, sharing learning around engaging service users and the development of regional improvement measures. They have worked together regionally to co-design improved response times, develop appropriate regional outcomes measures, improve user engagement through the increased use of social media and technology and by creating users forums amongst other initiatives, ensure equipment is made available in a timely way, provide appropriate clinical assessments environments and address workforce and information management systems.

Portsmouth City Council and Portsmouth CCG Integrated Commissioning Unit[76] worked with NHS Solent to implement the findings of a review of wheelchair services in the area. As a result NHS Solent committed to the provision of a new wheelchair service with an emphasis on: a holistic pathway, a person centred approach taking account of clinical needs and lifestyle requirements, integrated working with social care, target waiting times (two days for stock chairs, within 15 days for non-stock), an annual planned maintenance and emergency out of hours service and relocation of services to a more accessible location.

NHS Calderdale, Greater Huddersfield & North Kirklees CCGs Wheelchair Services[77] commissioned their Commissioning Support Unit (CSU) to undertake a review of their current services. The three CCGs were concerned that services were overstretched and overspent, and there was a lack of understanding as to why that should be the case. Some of the issues identified in this review are set out elsewhere in this eDigest.

Due in part to the findings of this work, wheelchair services for these CCGs were co-designed and re-commissioned in 2014 in partnership with wheelchair users, their families and carers. Their aim is to ensure that the wheelchair services provided reflect the holistic needs of users, with reduced waste, improved experience and lessened harm.

Advanced Prescribing for Patients with a Rapidly Progressive Condition – Motor Neuron Disease (MND)[78] - uses additional therapists to make links with local and regional wheelchair centres. They aim to support delivery of timely, appropriate assessments and wheelchair provision to people with MND; to be a resource to other professionals as and when required; to support in service development and promote the use of advanced prescription; to work with three leading wheelchair manufacturers to develop and review the 'Neuro' power wheelchair prescription to ensure the chairs and features continue to meet the needs of people with MND. They also aim to make links and develop pathways to ensure people with MND get timely access to appropriate communication aids and environmental controls, which can then be integrated and mounted onto the wheelchair.

The outcome for the individuals and the whelchair service is stated to be improved pathways with fewer re-assessments and removed need for chair re-provision. This process results in cost savings for the service in terms of therapy and rehabilitation engineering (RE) time and procurement of equipment at reduced costs. The outcomes for the person with MND is more person centred, promoting long and short term independence. The MND Association was awarded a grant by the DH to extend this project from the original site in Oxford to two additional sites. These are located in Leeds Wheelchair Service and the Queen Elizabeth Foundation Mobility Centre in Surrey.

Beginners Guide to NHS Wheelchairs 2014[79] - developed by The Leeds Teaching Hospitals NHS Trust is a free resource on YouTube offering five video clips with useful information and tips to help new wheelchair users. There is advice on how to use a wheelchair, transportation, and maintenance. The videos also explain the parts of a wheelchair. Evidence shows the importance of skills training[80] for wheelchair users. For example, a 2012 study of a two day skills training for children[81] suggests that following training participants could do more, with less pain and fatigue. Similarly, a study with older adults found that wheelchair skills training improved confidence.[82]

Disability Matters is a programme led by the Royal College of Paediatrics and Child Health (RCPCH) on behalf of a consortium of disability charities and medical bodies including the Council for Disabled Children. Disability Matters addresses the challenges and barriers that disabled children and young people face by enabling all individuals to reflect on, challenge and positively change their own fears, ideas, attitudes and beliefs towards disability and disabled children and young people. It provides free online resources for those who work or engage with disabled children, young people and their families, which can be used for personal learning and as part of facilitated workshops that can be co-delivered by disabled young people and parent carers. These resources have been co-developed with disabled young people and parent carers, giving voice to their lived experiences and offering practical advice about supporting disabled people to achieve the outcomes that matter to them. As part of this work they will be creating a learning package for people who commission disability services, including wheelchair services.

The voice of a healthcare professional:
A healthcare professional discusses Disability Matters.

WHAT DO WE NEED TO DO?

In bringing together the key research findings to answer the question *"Do we have an intolerable situation with wheelchair services in England?"* *"What does the evidence base tell us about the current state of wheelchair services in England, in relation to people with complex and changing needs, and its impact upon people's lives and health, care and voluntary services?"* the evidence makes it very clear; whilst there are areas of great practice around the country there is indeed an intolerable situation in wheelchair services for people with complex and changing needs in England.

The evidence shows that there are many wheelchair professionals providing an excellent service and experience for their wheelchair users and their carers or who are championing initiatives to significantly improve wheelchair service provision in local areas.[83,84,85] Sadly the evidence has also demonstrated that this is not always the case.

> **"We hadn't had an appointment at the NHS wheelchair unit for about two years because I'd got a private chair. I didn't realise we were still entitled to NHS wheelchair services until I went to a clinic appointment and the consultant had mentioned he was concerned about his posture and I explained I'd got a problem with the wheelchair. I sometimes wish I'd never come out of the NHS system. It was really good, I was really impressed with it in the first years of Nathans life, the reason I opted to get a private chair was because I wanted to get something more lightweight and easier to propel to increase his independence."**
>
> **Eileen, mother of Nathan,**
> **a wheelchair user**

Numerous reports have repeatedly shown that there are often significant delays in wheelchair provision, significant variation in assessment, fragmented procurement, poor maintenance of existing wheelchairs, poor communication between wheelchairs services and wheelchair users and lack of co-ordination between service providers.[86] The evidence also shows that there is a very heavy reliance on voluntary services and carers to bridge the acknowledged gaps.[87,88]

These well documented issues have, at times, created a very poor user experience at best and actual harm and waste, from issues such as pressure ulcer, postural damage and mental health impacts, in the very worst cases. These impacts also impact negatively on the health and care system, with increased costs associated with secondary complications having a significant effect on both very limited health and care resources and on society in general.[89]

The evidence base has also told us that we don't always know if people are getting what they need, when they need it, from wheelchair services as people might be getting what they need provided from services outside the NHS. There is no data held by the NHS about the number of people buying their own wheelchair or turning to a charity for support. Knowing this would help us to understand the scale of the problem.[90]

The evidence makes it very clear that there is a need to collectively act now, to ensure that the available tools and guidance, and best examples of wheelchair service provision, are replicated appropriately around the country. This will enable us to stop the harm, waste and poor experience caused by the current levels of variation and share much more widely the positive experiences. It also shows that there is a great willingness to act from key stakeholders and a huge appetite from wheelchair users and their carers to be part of this action but that this needs to be co-ordinated and joined up.[91,92]

The good news is that there is evidence that this improvement work has already begun. There was a strong recognition at the first wheelchair summit that organisations and government should work together to address this intolerable situation. NHS England committed to support this by tackling some of the system levers that will help to make a positive change.[93] This evidence review validates this work and suggests that the commitments to act from NHS England that are already underway should continue with vigour in addressing the three identified priority areas in relation to a national data collection, the piloting of a tariff for wheelchairs and the development of an outcomes-based service specification.

However the evidence also makes it clear that addressing system levers alone is not enough. There is a desperate, recognised need to align improvement activities and to mobilise everyone associated with wheelchairs to make their personal contribution towards improving this situation; improvements that build upon the commitment of all staff, from all services, wheelchair users, their carers and their families.[94,95]

To support the improvements needed and wanted by everyone we have spoken to, this evidence review suggests the following additional actions are required:

- To consider the creation of a wheelchair alliance to bring representatives of all key stakeholder groups under one umbrella group to help orchestrate a collective response to the improvement approach
- To co-design a wheelchair services improvement campaign that mobilises all involved with wheelchair services to work collectively to make a lasting, positive change
- To create a wheelchair ‘constitution’ that all services will commit to and act on, that sets out what good looks like and reminds us of the rights people have.

WHAT CAN WE ACHIEVE TOGETHER?

The evidence provided within this eDigest quite clearly shows that where we all work together we can make a significant, positive difference to the quality of life for those people and their carers who rely on wheelchair services. In fact we would say that without working together we cannot solve the problem: this has been tried before. By improving the quality of the user experience we can also use NHS and care services resources much more effectively. And the voice of wheelchair services and wheelchair users can be enhanced by the introduction of a Wheelchair Leadership Alliance to champion this cause at a national level and through the development of a wheelchair constitution that we can all commit to and act on, that sets out clearly for all what is expected of wheelchair services.

If we harness the evident desire to work together to improve the current standard of wheelchair service provision the evidence suggests that we can expect to:

- Consistently provide a positive experience of wheelchair services for all wheelchair users and their carers no matter where they live or how timely their need, ensuring that there are no more reports of individuals coming to harm or even dying before their wheelchair is available
- Reduce the unacceptable delays that sometimes occur in respect of wheelchair provision
- Significantly reduce harm: the risk of secondary complications and all associated costs to the benefit of the individual, their family, carers and society in general
- Achieve the desire to support wheelchair users to lead as full and as active a life as they choose, creating equality with a freedom that non wheelchair users take for granted
- Support staff with the right skills to co-produce solutions with people who are seen by them so that the above outcomes are met.

There have been enough delays. We are asking the system to act now and together. If we do we can expect to achieve our collective desire:

RIGHT CHAIR
RIGHT TIME
RIGHT NOW

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