

# Sitting Comfortably

Listening to the experiences of adults and children using wheelchair services in Cambridgeshire and Peterborough



## Healthwatch Cambridgeshire

Our role is to make sure local people have a say when important decisions are made about their health and social care services.

We find out about people's experiences of care and share them with the organisations who make the decisions, to help them improve care where it is needed. If care is not working in the way it should, then we have statutory powers to challenge health and care decision makers.

We are independent and local. Our Healthwatch is part of a national network through Healthwatch England, and we have direct links with regulatory bodies such as the Care Quality Commission and Monitor.

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# Background

*'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.'*

Baroness Tanni Grey-Thompson



Baroness Tanni Grey-Thompson, describing the importance of her wheelchair. She reflected the feelings of all wheelchair users in the report produced in November 2014 by the Right Chair, Right Time, Right Now campaign, published by NHS Improving Quality. The report highlighted the concerns of wheelchair users about services across the country.

The campaign has also produced and promoted a good practice charter which sets out ten areas that would improve people's experiences. It asks organisations to support the development of an NHS wheelchair service that can deliver a fair and effective service for all people who need to use it and to commit to these principles.

**The ten areas are grouped into these themes:**

- Equality of access.
- Integrated budgeting across health and social care.
- Person-centred Assessments within nationally agreed time-scales.
- National standards for delivery, maintenance and emergency backup.
- Support and training for all staff including clinicians, manufacturers and independent organisations.
- Affordable and innovative products and solutions.

The charter principles are listed in full in the appendices to this report.

## Wheelchair services in Cambridgeshire and Peterborough

In our area, wheelchair services are commissioned by Cambridgeshire and Peterborough Clinical Commissioning Group (CCG). The organisation Provide delivers the services, and maintenance services are primarily provided by Bartrams.

Organisations in Cambridgeshire that represent children, their families, and adults with disabilities have been hearing of people's dissatisfaction with local specialist wheelchair services for a number of years.

Pinpoint is a local voluntary organisation that offers information, support and involvement to Cambridgeshire parent carers, especially those with children with additional needs and disabilities. It had been raising concerns from children and young people using wheelchairs with both the local wheelchair service and CCG, since 2013. When Pinpoint surveyed their members in 2014, 86% of people responding said they were dissatisfied with the service.

### They reported concerns about:

- The coordination and administration of the services.
- Delivery, maintenance and repair.
- Handling of complaints and the provision of information.
- How the wheelchair itself met the needs of the children and young people.

Organisations and individuals also reported concerns at the Cambridgeshire Carers Partnership Board facilitated by Cambridgeshire Alliance for Independent Living (CAIL). The issue of wheelchair service provision was regularly on the Board's agenda, and the commissioners were invited to meetings to hear concerns on a number of occasions.

Hearing peoples' stories, Healthwatch Cambridgeshire and our partner 'voice' organisations have collected more information from wheelchair users and their families and carers in Cambridgeshire and Peterborough about their experiences of using wheelchair services. This report summarises what we heard and what needs to change.

# What we did

We worked with local voluntary sector organisations to collect stories from people using our wheelchair services. We took a mixed approach to gathering experiences, to make the process as easy as possible. People were able to chat at drop in sessions, meetings or talk to our volunteers in a place of their choosing.

We organised an online survey. We also made arrangements to listen to groups of people with high support needs with their support workers. Some people may have chosen to chat to us and complete the survey.

This report reflects the experiences of those wheelchair users, carers and families, who chose to get involved and talk to us. It does not represent everyone's experience of the service.

## Drop ins

CAIL hosted two drop in sessions in Papworth, a village in South Cambridgeshire where a higher than average number of wheelchair users live, to hear people's experiences. Some wheelchair users who were unable to get to these sessions were interviewed to share their stories. We have summarised these below, but you can read the full list of people's comments in the appendices.

## What did people say?

There are lengthy waits:

- For an assessment.
- For a wheelchair.
- For repairs.

People also experienced:

- Poor communication.
- Poor coordination and administration.
- Wheelchair not meeting users needs.

## Our survey

The survey was designed by staff from Healthwatch Cambridgeshire, CAIL, and Pinpoint. It was modelled on Pinpoint's earlier survey of parent and carers perceptions of local services, so some comparisons could be made when looking at the results from the survey. It also took into account what people had said at the drop in sessions and in one to one interviews.

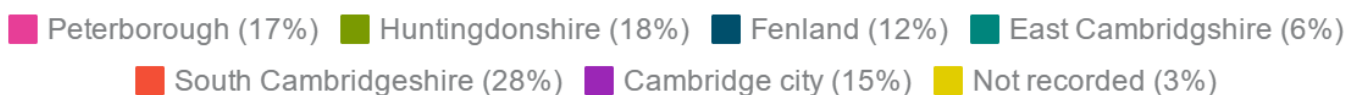
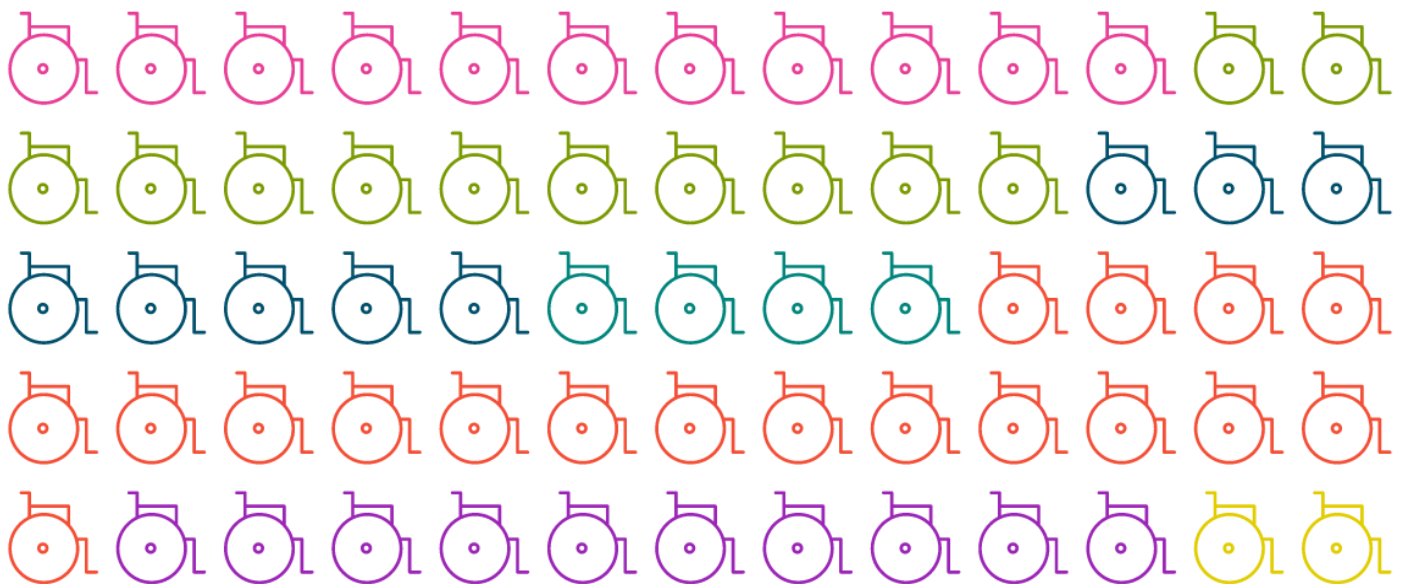
The survey was available on Healthwatch Cambridgeshire’s website from early December 2015 to the middle of February 2016.

All the partner organisations encouraged people to complete the survey online, using a range of media to draw attention to it. Healthwatch Cambridgeshire staff and volunteers encouraged people to complete the survey whenever we were out talking to people at events such as Pinpoint’s annual conference, Cambridge City Council’s Disability History Month event, and CAIL’s ‘Access All Areas’ event, and at local community events. A flyer promoting the survey went out to parents at the special schools in the area.

The partner organisations encouraged other organisations supporting people with disabilities and their carers to promote the survey through newsletters and contacts. Cambridgeshire County Council’s Partnership Boards, all of which are facilitated by CAIL, were kept up to date about the work.

Questions in the survey asked people about themselves, their type of wheelchair, their experiences of using the local wheelchair services, and to what extent they (or their carer) felt their wheelchair meets their needs. The survey was completed by wheelchair users themselves, parents and family carers of wheelchair users, and a small number of paid carers and professionals.

**The survey was completed by 65 people from across the county.**



24 wheelchair users were under the age of 25, 28 users were aged between 25 and 64, and 18 were over the age of 65. A quarter of those responding (16) have powered wheelchairs, and just under three quarters (46) used manual wheelchairs.

## Speak Out Council and High Support Needs group meeting

We met with members of the Speak Out Council's High Support Needs group. This is a group of young adults with multiple and complex needs and all of them are dependent on their wheelchairs. With help from their support workers we talked about their 'dream chair'. They also told us about what was important to them about their wheelchairs.

We heard about:

- The challenges of needing to be able to fix additional pieces of equipment to their chairs, such as communication aids and tables, without compromising the function of both the chair and the other items.
- How often chair parts are broken and the delays in getting them repaired.
- That it was crucial that their chair was the right size, that they were comfortable to sit in for long periods of time, and that their seating is shaped appropriately to maintain good posture.
- Concerns that staff in the wheelchair service seem unable to see the Wheelchair user's individual needs.

Young people who are a part of Sense's (Cambridge Resource Centre) Learners Group also worked on making a picture of what they wanted from their wheelchair with the support of the Speak Out Council Coordinator. They told us how important it is that their wheelchair meets their individual personal needs and how they felt that this need for personalisation was often overlooked.

### The Learners wanted:

- As much control as is possible when in their wheelchair.
- More choice of colour and texture, for example, with wheels, cushions, frames.
- Lights which would enable them to be able to be safer when out in the dark.
- Noises so that people could hear them coming.
- Comfortable wheelchairs, particularly to help protect them from sudden jolts on uneven pavements.



 A motor

 Lights

Tray to work on

 The right size for me.

 Nice to look at.

 A control stick

 Seat shaped for me.

 Big battery

 Foot plates.

 Smart



# What people told us in the survey

Are people happy with the service they receive?

*'As a frequent NHS user, the wheelchair service is one of the only areas which I have had to make numerous complaints about.'*

*It is poorly organised, inefficient and could be much, much better. I dread my son having any requirements from this service.'*

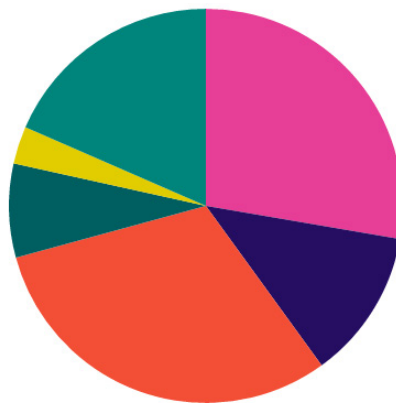
*'The wheelchair service does not offer a suitable service and needs to be completely looked at again'*

*'Very poor overall service. No support. Holding back child's development, progress and independence. Leaving families housebound. Socially excluded.'*

*Inadequate provision to support other healthcare provision. Potentially causing more long term problems for our daughter.'*



40% (26) of those replying to the survey rated their overall satisfaction of the service as poor or very poor, 10% (7) as good or very good, 30% (20) reported their level of satisfaction as being mixed.



Very poor (28%) Poor (12%) Mixed (31%)  
Good (8%) Very good (3%) Not stated (18%)

We were interested to know if levels of satisfaction differed depending on how recently people completing the survey had experienced the service.

61 people told us when they had used the service. Just over half had used it more than a year ago, just over a quarter had used it within the last six months, and 20% between six and 12 months ago.



The survey asked people to rate their level of satisfaction with a number of aspects of the wheelchair services, including their experience of staff helpfulness, service coordination, the assessment (or reassessment), delivery of the chair or parts, and of servicing and maintaining the wheelchair. We also asked people to rate their level of satisfaction of the knowledge and skills of both the therapists and the support provided by Bartrams, who maintain and repair the wheelchairs.

At this level of the analysis the numbers from the survey are small, but do provide an interesting perspective on the service users experiences.

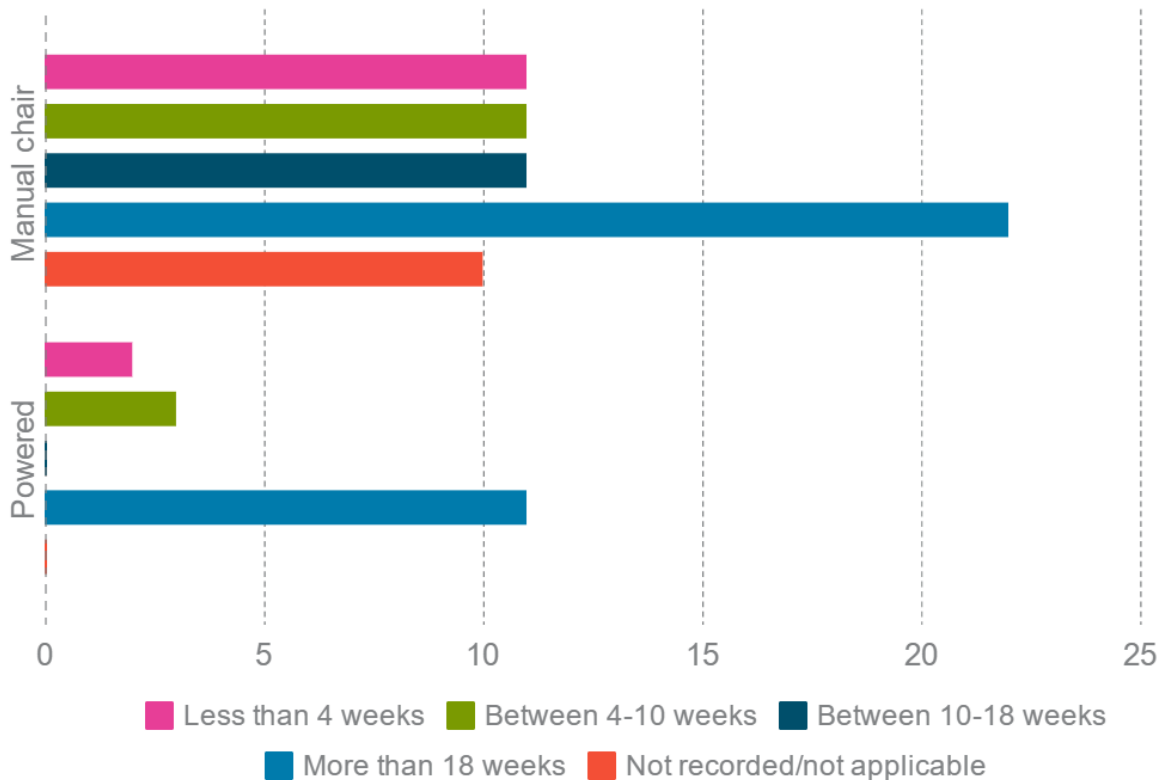
Only 6 people completing the survey had used the service less than 3 months ago. It is interesting to note that unlike people using the service longer ago, none of these people rated any aspect of the service as being 'very poor'. However, most aspects of the service continued to be rated as 'poor' or 'mixed'.

## How long did people wait for their wheelchair?

A number of people responding to the survey commented that they felt they had waited too long for their wheelchair.

We asked people how long they had waited between their assessment and receipt of their chair. We found that half of all people waited more than 18 weeks for their wheelchair. Under a quarter received their wheelchair in less than a month.

## Weeks waited



## Does the wheelchair meet your needs and those of your carers?

*'The wheels are positioned too far back for our son's arms to comfortably be in the correct position to propel himself. Wheel chair very heavy.'*

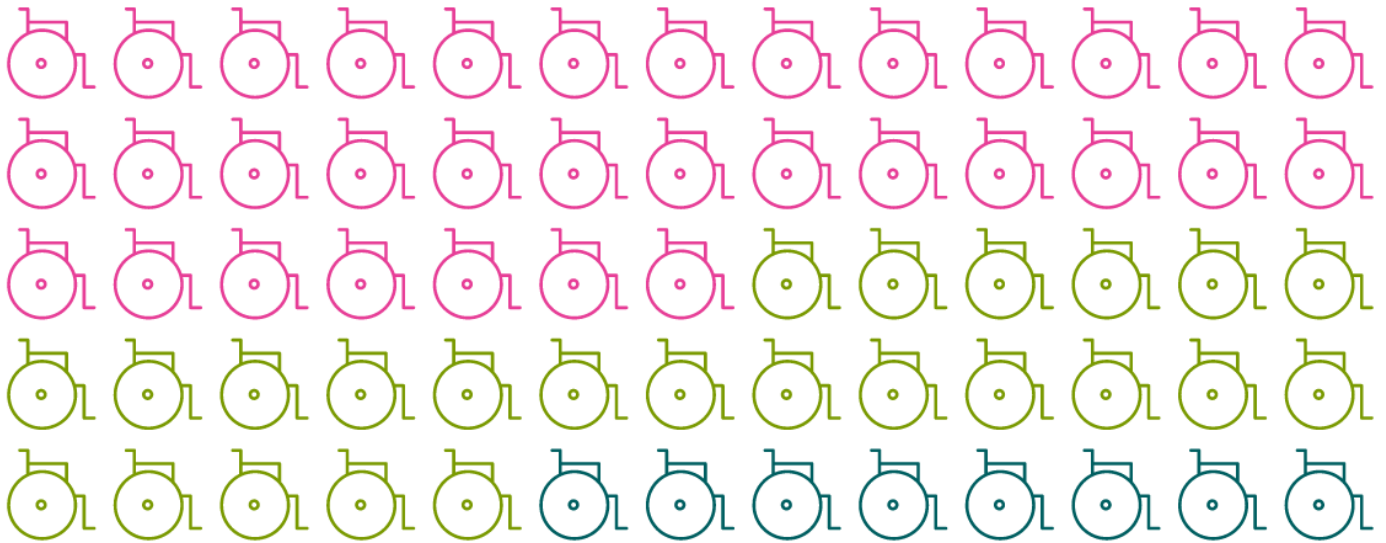
*'The front wheels too big and always catching on door frames etc. It is a little on the heavy side for me to manoeuvre easily.'*

*'The chair isn't wheelchair pusher friendly as the anti-tip is badly positioned so one kicks it constantly.'*

*'They should understand that our wheelchairs are our independence and life line.'*



Over half of the people completing the survey felt satisfied with their wheelchair, but a significant proportion, 37%, did not.



■ Satisfied with my chair (51%) ■ Not satisfied with my chair (37%) ■ No response (12%)

A number of people highlighted the difficulties faced by their carers and felt strongly that their carers' needs should be taken into account when providing a wheelchair.

*'Wheelchair is at a height fitted for primary care giver but does not always suit other carers needs due to low height for example, causing bad back care.'*



*'You [the service provider] need to take into consideration the needs of the person doing the caring and pushing as in my case.'*

*I am also physically disabled as well as the needs of the person using the chair.'*

## Did people think they received the right information from the service?

The survey also included questions about the provision of information, to find out if users were provided with information about:

- What they could expect from the service.
- The NHS voucher scheme (wheelchair users may be offered a voucher to the value of the chair they would have been offered after assessment to put towards the cost of a chair bought privately or in partnership with the NHS).
- How to feedback to the service about their experiences.
- How to make a complaint.

Following on from the Pinpoint survey, a leaflet had been designed to give the families of disabled children important information about the service. However, the overwhelming response was that people (including families with disabled children) had not received any information at all. Only four people out of the 65 people responding to the survey reported that they had received any information about the service, and one of these stated that the information had been in response to asking about how to complain. Six people were unsure whether they had received any information.

Responses to the survey showed a very low level of information being offered about the NHS voucher scheme for wheelchairs, or information around seeking alternative or additional funding.

In response to questions about complaints, 20 people answered the question asking if they had experience of complaining about the wheelchair service. Only one person said that they were happy with how their complaint was handled. Four people experienced a 'mixed' response, 15 of the 20 said they were 'unhappy' or 'very unhappy' with how their complaint was handled.

Responses to these questions did not differentiate between the wheelchair service provider Provide, and Bartrams. Service users often seemed to be confused about which organisation was responsible for what part of the service. Some had not heard of Provide and assumed that Bartrams were responsible for all the wheelchair service.

*'I would like them to publish information about all the wheelchairs available for someone like me so that I can make a decision with my therapist about the best one for me at this stage. It would also be useful to have some sort of a guide as to how often a wheelchair should be serviced and what you should look out for i.e. potential problems.'*

## What else did people tell us was important to them?

*'Wheelchair care needs to be individual specific. Some people sit still in their chairs, others dance all day.'*

*Wheelchairs last longer and therefore cost the service less if loose bolts are tightened etc. before bits drop off and get lost/broken.*

*All staff who put non verbal people in wheelchairs should be trained how to position the individual for optimum posture and should be taught how to tighten straps etc.'*

People shared their experiences of using their wheelchair, and wheelchair services with us at the drop in sessions, at meetings and events, and in the survey. We identified a number of key themes to their concerns about the service, the suitability of their wheelchair, lack of information and length of wait for the delivery of their wheelchair.

### Wheelchair maintenance and repairs

We heard lots of stories about the difficulties people faced in getting their wheelchairs maintained, unacceptable delays when chairs needed repairs and the problems these delays caused both the wheelchair user and their carers.

*'There are outstanding fitting tasks that I was assured would be completed in April 2014 which have not been undertaken, and a recent repair has been farcical.'*

*'The wheelchair user I support has a broken wheelchair, parts fall apart too easily, foot straps do not hold feet consistently.'*

*'If something breaks on my chair, I'm stuck. But nobody seems to care that I may not be able to move from my bed, never mind my house.'*

*'It took over thirteen days to replace a critical part, putting carer and disabled person in severe danger.'*



*'I have been waiting six weeks for a new cushion.'*

## Accessing the service

Service users, their families and carers describe trying to access the service as difficult, even for existing service users.

*'Often I have experienced delays in effecting a repair because of a lack of communication. It seems to take ages to get spare parts or parts have arrived but are not known about and are sitting somewhere on a shelf.'*

*'It should be much simpler and easier process.'*

*'When you ring, they do not pick up the phone. Then you leave a message and they say they will get back to you. It takes so long for them to do that and I have been told that my chair is not anywhere, then it is. I have been waiting since June 15.'*



*'very stressful.'*

*'Going around in circles.'*

*'The assessment staff are very good, so are the engineers - when they call. But the back room staff are very poor.'*

We heard many comments about poor communication and coordination, and how this caused further delays.

## The need for regular routine reassessments

Families of children and young people frequently told us of difficulties getting their child's wheelchair needs reviewed regularly, as they grew and their disability changed.

*'The wheelchair is now too small, he has outgrown it.'*

*'My son is growing quickly and he no longer fits well in it.'*



Adults too reminded us that their needs change over time and they also felt that they needed their wheelchairs to be reviewed, adjusted or replaced to meet these changing needs.



*'As time goes by my disability changes, but this service does not take that into account'*

*'The chair my husband uses is about five years old and we don't really know how to update it.'*

User and their families and carers seemed uncertain as to how often they could reasonably expect a routine reassessment, and whether the responsibility rested with them or with the service to try to arrange a reassessment.



# What needs to change?

Following the Pinpoint survey and subsequent conversations between Pinpoint, Provide and the Clinical Commissioning Group, improvements in the service were anticipated. However, the feedback about the service from the work done here suggests there has been little improvement levels of satisfaction with the service. Many people commented that they felt they encountered too many obstacles in trying to get assessments and reassessments, and waited too long for routine reviews. People felt that the service failed to acknowledge and act on peoples changing needs.

Cambridgeshire and Peterborough Clinical Commissioning Group will be recommissioning the wheelchair service in the near future. We expect the findings in this report and the comments people have made will be taken into account in both writing the tender for the service and in the commissioning process.

**Healthwatch Cambridgeshire recommends that:**

## 1. The wheelchair service sets and meets clear response times

We heard that wheelchair users felt that they often had to wait too long to be assessed, and for their chairs to be delivered with all the correct and functioning parts. Essential repairs often took a long time, and waiting for repairs often significantly affected their quality of life.

**Wheelchair users need a service that :**

- Responds promptly to service users' enquiries.
- Ensures that wheelchairs are provided to users as quickly as possible.
- Has clear and realistic guidelines, which are adhered to for prompt repairs and maintenance calls.

## 2. Coordination between different parts of the service must improve

We heard many comments about the poor coordination between different parts of the system. People commented about poor coordination within Provide, for example, between administration and therapists and between Provide and Bartrams' maintenance and repair staff. We heard about calls not being returned and messages not being picked up and acted on.

Poor coordination results in further delays within the system and considerable frustration.

#### **Wheelchair service users and their families need:**

- Clear information about who is eligible to use the wheelchair service, how to access it and what to expect from the service.
- To be confident that the system is coordinated effectively.

### **3. The service is responsive to the individual needs of wheelchair users**

People told us how important their wheelchair is to the quality of their lives but equally importantly they told us that their wheelchair needs were specific to them their disability and their own individual circumstances. Too often people felt the importance of personalisation was overlooked.

#### **More effort must be made to ensure that:**

- Wheelchairs meet all the users' individual needs.
- Users and their family/carers feel that they are listened to.
- There is a clear understanding between staff and wheelchair users and their families about when and how their wheelchair needs will be regularly reassessed.

# Appendicies



# RIGHT CHAIR RIGHT TIME WHEELCHAIR CHARTER



**It is estimated that 2% of our population use wheelchairs to get to work, go to school, buy their groceries, look after their children, contribute to our society and achieve their goals.** Sadly many of them don't fulfil their aspirations because the current wheelchair services fail to meet their needs.

Currently we see great variation in ability to access assessment and obtain service provision, delays in repairs and equipment, poorly thought through provision plans and patient pathways, confusing information, restrictive and inflexible funding and minimal integration of services.

And throughout all of this are the service users struggling to carve out the kind of lives they would wish to lead.

As a group, the Wheelchair Leadership Alliance has committed to make the kind of changes that will truly improve the lives of these service users and their families. But we cannot do this alone - we need your help.

By signing up to this charter as service users, providers, voluntary sector organisations, commissioners, clinicians and members of the public we will together be able to start the change and commit to better services and an improved quality of life for every wheelchair user.

By signing this charter you are pledging to support the development of an NHS wheelchair service that can really deliver a fair and effective service for all people who need to use it.

## We pledge our commitment to:

- 1 A person centred service that works in partnership with service users and their carers and makes the user/carer voice central to any design, innovation and service change.
- 2 Equality of access and provision for all, irrespective of age or postcode and including essential user skills training as standard.
- 3 Entry to service via referral from an appropriately skilled professional. The time from referral to delivery will be at least within the constitutional right of 18 weeks with further substantial improvements by 2016/17 for all people using the service.
- 4 Assessments for all wheelchairs and associated postural support within nationally mandated timescales and priorities taking into account all aspects of individual needs including those of carers.
- 5 Establishing regular reviews with the user/carer according to their individual needs.
- 6 Prescriptions which take into account the current and future needs for all adults and children including those of carers.
- 7 Delivery, maintenance and emergency backup provided to nationally mandated timescales.
- 8 Innovative and flexible budgeting working with key partners to strengthen integration across health, social care, work and education, enabling the accommodation of individual needs, independence health and wellbeing.
- 9 Recruitment of qualified staff in respect of numbers and skills, with support for on-going development and training.
- 10 Supporting clinicians, manufacturers and independent organisations working together to develop innovative, affordable products and solutions.

Signature: .....

Representing: .....

Date: .....



## WHAT DOES THIS MEAN?

- 1. A person centred service that works in partnership with service users and their carers and makes the user/carer voice central to any design, innovation and service change.**  
All wheelchair service staff working effectively with individual users (and their carers) to make sure any equipment provided really meets their needs. This principle also requires commissioners and providers to commit to proper user/carer input when planning and making changes to the services
- 2. Equality of access and provision for all, irrespective of age or postcode and including essential user skills training as standard.** The end of the postcode lottery in terms of both ability to access the service and provision of equipment. This would prevent confusion and disadvantage when education needs mean a user moving to another area and/or changing GP. It enables acceptance of equipment prescriptions issued in other areas and an end to arbitrary age discrimination. This is especially the case where very young children may or may not be provided with chairs depending solely on where they live.
- 3. Entry to the service via referral from an appropriately skilled professional.** The time from referral to delivery will be at least within the constitutional right of 18 weeks with further substantial improvements by 2016/17 for all people using the service. An end to eligibility criteria based on rationing and replaced with usual NHS referral methods where appropriate clinicians refer to the service because of clinical need, irrespective of whether for manual or powered chairs or postural support. An immediate recognition of the constitutional right for users to have their needs met within 18 weeks, with the necessary data collected to ensure it happens. Recognition of urgent need and activation of speedy referral to delivery times to meet it. Commitment to making substantial reductions in the referral to delivery times by the next financial year for everyone who uses the service and to collecting and monitoring the data to ensure it happens.
- 4. Assessment for all wheelchairs and associated postural support within nationally mandated timescales and priorities, taking into account all aspects of individual needs including those of carers.** Everyone referred gets a timely assessment, which takes account of their individual needs as well as those of their immediate carers. Assessments would be measured against nationally agreed timescales, priorities & standards and the practice of denying assessment in certain circumstances because of rationing eligibility criteria would cease.
- 5. Establishing regular reviews with the user/carer according to their individual needs.** Ensuring health and wellbeing, pre-empting problems and ensuring timely adaptations for more complex cases. Allowing easy access to users and their carers without them having to be re-referred and start the process all over again
- 6. Prescriptions which take into account the current and future needs for all adults and children including those of carers.** Prescriptions that really provide for individual users, both in terms of meeting their needs in the short term and anticipating likely changes. This includes making sure wheelchairs are light enough to ensure full use by the user and their carers, or equipped to anticipate changes in condition, development or changing environments. It would also include posture support as well as type of chair and/or any add-ons e.g. risers, facilities for communication aids, head supports etc. As well as meeting individual needs, it would be much more cost effective over a longer period of time as it would eliminate the waste of an unused chair or the extra costs of assessing and providing adaptations which could have been predicted and provided initially, at an overall lower cost.
- 7. Delivery, maintenance and emergency backup provided to nationally mandated time scales.** Ending unnecessary delays by working to agreed national timescales to ensure the right chair is provided as soon as possible. It would also bring the reassurance of rapid turnaround times in both emergency and routine maintenance and prevent the isolation and physical restrictions many wheelchair users confront when a chair is unavailable to them. Development of strong links with manufacturers & regional wheelchair services and closer working together to provide effective solutions and shorter timescales for delivery.
- 8. Innovative and flexible budgeting working with key partners to strengthen integration across health, social care, work and education, enabling the accommodation of individual needs, independence, health and wellbeing.** Cutting through the rationing of provision by: a) Collecting the data and costs so that numbers are accurately known and can be properly resourced. b) Proper integrated working across all current funding agencies to maximise efficiency and provision effectively and quickly. Integration is a key component which can maximise efficiency of resource allocation for the service providers whilst enabling wheelchair users to access what they need to function effectively. c) being creative with funding e.g. shared costs, allowing individual contributions or voluntary sector partnerships whether for particular chairs or additional functions e.g. risers. d) working across CCGs regionally or nationally to negotiate large scale and well-priced contracts and reaping the benefits to provide what is needed to enable wheelchair users to function effectively and embracing newer technologies at affordable prices. e) Budgeting flexibly. Short-term spend on better chairs can lead to long-term saving both in other NHS areas (avoided surgery, pressure sores and mental health treatment) and beyond NHS budgets (reduced assistance in education and in welfare benefits; increased employment). Consider costs over the equipment's lifetime, rather than its impact only in the year in which it is prescribed.
- 9. Recruitment of qualified staff in respect of numbers and skills, with support for ongoing development and training.** Resourcing the services with the right number of staff to meet standards. Making sure that training is in place to support existing staff and to develop new trainees, whether by supporting outside training courses, or developing in house or pan-regional courses. This needs to be for all staff, specialist therapists, engineers and technicians, providing a career structure and recognising their need for continuing professional development.
- 10. Supporting clinicians, manufacturers and independent organisations working together to develop innovative, affordable products and solutions.** Developing and supporting strong links between all agencies involved in providing services and products and fostering integrated working to bring about advances and new technologies and create affordable advanced solutions. This means supporting specialist therapists, engineers and manufacturers to work closely together and giving them the opportunity to explore new technologies and new ways of doing things.

*Run by people with disabilities, for people with disabilities*



### Experiences of people who use the Cambridgeshire Wheelchair Service

27<sup>th</sup> August 2015

Author: Graham Lewis, Voice Network Coordinator

#### Background

The Cambridgeshire Alliance for Independent Living (CAIL) is an organisation run by people with disabilities for people with disabilities, their families and their carers. We believe that every person with a disability or long term health condition should be treated with respect and have equal rights and opportunities; they should be able to control and manage the support needed to live independent lives as full and valued members of the community. We also want to raise awareness and improve everyone's understanding about the crucial role carers play in supporting other people.

We do this is through two of our projects:

- Voice Network Project which listens to people about their lived experiences of living with disability and the issues that make life more difficult.
- Cambridgeshire County Council's Adult Social Care Partnership Boards, which aim to improve the services they offer to people with disabilities, their families and their carers

Between May 2014 and August 215 people who use the Cambridgeshire Wheelchair Service (a commissioned service managed by Provide) had been telling us of their concerns about the wheelchair service at CAILs projects.

These initial concerns were discussed with Healthwatch Cambridgeshire (the patient watchdog) and it was agreed that CAIL and Healthwatch would promote a 'call to action' asking more people to tell us about their experiences.

As part of the call to action, drop in events were organised at the Cambridgeshire Alliance for Independent Living offices in Papworth Everard on:

- Tuesday 21<sup>st</sup> July
- Thursday 6<sup>th</sup> August

These drop in events were promoted by:

- Facebook (Cambridgeshire Alliance)

Cambridgeshire Alliance for Independent Living

Lower Pendrill Court, Ermine Street North, Papworth Everard, Cambridge CB23 3UY

Tel: 0300 111 23 01 Email: [info@cambridgeshirealliance.org.uk](mailto:info@cambridgeshirealliance.org.uk) Web: [www.cambridgeshirealliance.org.uk](http://www.cambridgeshirealliance.org.uk)

Registered Charity No. 1132290 Company limited by guarantee No. 06861653



- Twitter (both Cambridgeshire Alliance and Healthwatch Cambridgeshire)
- Cambridgeshire Alliance website
- Cambridgeshire Alliance information bulletin to members and partner organisations
- Posters in Papworth Everard, where the Wheelchair Service is located.

If people were unable to attend the drop in events they could email or phone the office to tell us about their experience, or a home visit could be arranged.

Overall 13 people who are either wheelchair users or are carers for people who are wheelchair users (this excludes support workers of people who are wheelchair users) either attended the drop in sessions or contacted the office to express their thoughts and views on the wheelchair service.

### What did people tell us:

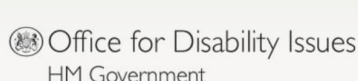
- 'long waiting times' for initial assessment and then have to wait for the chair to arrive
- That unless you have a spare chair you can be 'stuck in bed' whilst you wait for assessment or for it to arrive
- being spoken down to by staff members
- a feeling of not being listened to
- Appointments being cancelled by the wheelchair service but that they hadn't notified the service users, who attended the appointment
- If you required an urgent repair and the wheelchair was not usable you have to wait for them to come out
- Having to wait 3 years for an assessment for a new chair, the new chair is being made, but that the Wheelchair Service keep saying they will finish it soon
- That the current chair is no longer right for her, her arm and knee now hurt because of the poor support the chair provides
- The chair is not right, has foot rests which have to be removed when user goes to the toilet
- The seat is not comfortable so has to go to bed at 5 as gets a 'numb bum' after sitting in it for a long time
- That seat is very uncomfortable, Occupational Therapist (OT) said it would be replaced in 6 months, after a year nothing had happened. OT was contacted, person felt that they had been forgotten, appointments were made then put on hold, they never got back. Finally after 18 months fittings were done and some progress made, still have no new seat and its very uncomfortable to sit in chair all day
- really bad at communicating with service users
- the repair service is good, they go out of their way to fix chair
- been waiting for a year for new chair, old chair is no longer suitable, has to be repaired constantly

#### Cambridgeshire Alliance for Independent Living

Lower Pendrill Court, Ermine Street North, Papworth Everard, Cambridge CB23 3UY

Tel: 0300 111 23 01 Email: [info@cambridgeshirealliance.org.uk](mailto:info@cambridgeshirealliance.org.uk) Web: [www.cambridgeshirealliance.org.uk](http://www.cambridgeshirealliance.org.uk)

Registered Charity No. 1132290 Company limited by guarantee No. 06861653





- 6 months to wait for referral, 6 months for new chair - still not got, took a long time and had to ring/pester constantly to get in touch to find out what is happening, very negative feelings about the service
- very bad communication, no phone calls, lost letters
- original referral was lot, had to do it all again, appointments get cancelled, has even turned up for appointment to find it cancelled
- bad communication, doesn't know when chair is coming
- chair now very uncomfortable, no longer appropriate for body shape
- bartrums are all right, but no joined up communication, no linked working with wheelchair service
- new chair was ordered beginning June still not arrived (beginning of August)
- referred to wheelchair service for a manual chair, but on assessment offered electric chair - chair is now 3 years old
- bartrums have been out 20/30 times - recently engineer attended but did not have the right part
- front right castor lifting off floor, rang bartrums in the spring.. The in July went to supermarket the front left castor also went and so fell out of chair
- was hit by car, wheelchair service would not provide a new one, rang MP, wheelchair service then provided new chair
- wheelchair assessed and ordered in January, chair arrived without necessary parts mid april, bits and pieces finally fitted and accepted mid July

### What will happen next?

Healthwatch Cambridgeshire and CAIL will provide themed information to the Cambridgeshire Wheelchair Service and to its commissioner, Cambridgeshire and Peterborough Clinical Commissioning Group.

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"Wheelchair for you" is a joint project to help improve local wheelchair services for adults and children in Cambridgeshire and Peterborough. To do this we need to find out about your experiences with wheelchair services. We want to know what works well and what needs to be improved.

You can fill in this survey if you use a wheelchair yourself, or care for someone who does. If you are completing the survey on behalf of someone else, please tell us about them when you are answering questions about age, ethnic group, etc.

We will share what you tell us with the wheelchair service and its funder Cambridgeshire and Peterborough Clinical Commissioning Group (CCG), in a way that does not identify you.

- Provide is the organisation who provides and maintains wheelchairs for you, if you are unable to walk or have a long-term disability which affects your walking.
- Bartrams is the organisation who provides engineers to maintain wheelchairs.

---

### 1. What type of wheelchair do you have?

- Manual Wheelchair       Powered Wheelchair  
 Specialist pushchair  
 Other - please tell us : \_\_\_\_\_

### 2. Where do you live?

- Cambridge City       East Cambridgeshire  
 Fenland       Huntingdonshire  
 South Cambridgeshire  
 Peterborough (We will share your responses in full with Healthwatch Peterborough)

### 3. How old are you? We need to know this, as the service you receive depends on how old you are, particularly if you are under 25 years

- 0-5 years       6-11 years       12 - 17 years       18 - 24 years  
 25 - 34 years       35 - 44 years       55-64 years       65 - 74 years  
 75 years +

**4. When was your last experience of a wheelchair assessment or re-assessment?**

- Less than 3 months       Between 6-12 months  
 Between 3-6 months       Over a year

**5. From your last assessment, how long did it take before you received your wheelchair?**

- Less than 4 weeks       Between 10-18 weeks  
 Between 4-10 weeks       Over 18 weeks

**6. When was your wheelchair last serviced?**

- Less than 3 months       Between 6-12 months  
 Between 3-6 months       Over a year

**7a. If you get your wheelchair from Provide, please tell us about your experiences in the following areas?**

	Very good	Good	Mixed	Poor	Very poor	Not applicable
Helpfulness of staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Co-ordination of the service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assessment or re-assessment for your wheelchair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting your chair or parts delivered	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Servicing or maintaining your wheelchair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>

7b. If you get your wheelchair from another supplier, please tell us about your experiences in the following areas?

	Very good	Good	Mixed	Poor	Very poor	Not applicable
Accessing the voucher scheme from Provide	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Getting or finding additional funding for your wheelchair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting information from Provide on how to find a suitable wheelchair supplier	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting an assessment or re-assessment for your wheelchair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. Are you satisfied with the knowledge and skills of the following professionals?

Therapists	Very good <input type="radio"/>	Good <input type="radio"/>	Mixed <input type="radio"/>	Poor <input type="radio"/>	Very poor <input type="radio"/>	Not applicable <input type="radio"/>
Bartram's engineers	Very good <input type="radio"/>	Good <input type="radio"/>	Mixed <input type="radio"/>	Poor <input type="radio"/>	Very poor <input type="radio"/>	Not applicable <input type="radio"/>

9a. Have you been given information about the following, e.g. a leaflet?

What help you can get from the wheelchair service	Yes <input type="radio"/>	No <input type="radio"/>	Not sure <input type="radio"/>	Not applicable <input type="radio"/>
How to feedback on your experiences with the wheelchair service	Yes <input type="radio"/>	No <input type="radio"/>	Not sure <input type="radio"/>	Not applicable <input type="radio"/>
How to make a complaint about the wheelchair service if you need to	Yes <input type="radio"/>	No <input type="radio"/>	Not sure <input type="radio"/>	Not applicable <input type="radio"/>

9b. Was this information given to you in a format you could easily use?

Yes  No  Not Applicable

10. If you have previously complained about the service you received, were you happy with how the complaint was handled?

Very happy     Happy     Mixed     Unhappy     Very unhappy

11a. Does your wheelchair meet your needs? \*     Yes     No

11b. If not, please tell us why.

12a. What is your overall opinion of wheelchair services?

Very good     good     Mixed     poor     Very poor

12b. Are there any other areas of your wheelchair care that it is important for the people who make decisions about wheelchair services to know about?

**About you.** You do not need to answer the questions in this section. We are asking them to help us make sure we are listening to the experiences of as many people as we can. The categories are chosen as they are the ones used by Provide.

Are you?     Male                       Female

What is your ethnic group?

White     Mixed             Black or black British     Asian or Asian British  
 Chinese     Other             I do not want to tell you

**Your contact details.**

We will only contact you if you have given us permission to. We won't share your contact details with any other organisation without your permission.

Your name: \_\_\_\_\_

Your email address: \_\_\_\_\_

Your phone number: \_\_\_\_\_

Please tell us if you are happy for someone to contact you, to talk about your experiences in more detail? We may not contact everybody who gives permission.

Yes, I am happy to talk in more detail about my experiences of wheelchair services.

**We may use some of your comments in the final report but will make sure we do not identify you. Please tell us if you do not want to be quoted in the final report.**

I do not want my words to be quoted in the final report

How did you find out about this survey? \_\_\_\_\_

Please add me to your newsletter list.

*Thank you for sharing your experiences with us.*

This project is jointly supported by Healthwatch Cambridgeshire, Healthwatch Peterborough, The Alliance for Independent Living, Family Voice and Pinpoint.

Please support our "Wheelchair for you" survey by sharing it with people you know, and promoting it on social media using the hashtag #wheelchair4you.

To help us write our report, we will share your answers to this survey with Pinpoint, the Alliance for Independent Living, Family Voice and Healthwatch Peterborough.

### **Survey open until 14<sup>th</sup> February 2016**

**Please return your completed questionnaire to:**

**Freepost RTHA-RTYE-SATT, Healthwatch Cambridgeshire,  
Maple Centre, 6 Oak Drive, Huntingdon, PE29 7HN.**

**You can also complete it online at:**

**[www.healthwatchcambridgeshire.co.uk](http://www.healthwatchcambridgeshire.co.uk)**

**If you want to talk to someone about your experiences in more detail,  
please contact either**

**Healthwatch Cambridgeshire on 01480 420628 or email  
[enquiries@healthwatchcambridgeshire.co.uk](mailto:enquiries@healthwatchcambridgeshire.co.uk)**

**Cambridgeshire Alliance for Independent Living on 0300 1112301 or  
email [info@cambridgeshirealliance.org.uk](mailto:info@cambridgeshirealliance.org.uk)**

**Pinpoint on 01480 499043 or email [information@pinpoint-cams.org.uk](mailto:information@pinpoint-cams.org.uk)**

Healthwatch Cambridgeshire would like to thank all the organisations and individuals who have assisted us in collecting information for this report.

We would like to thank in particular:

- **Cambridgeshire Alliance for Independent Living**
- **Pinpoint**
- **Voiceability Speak Out Council**
- **Healthwatch Peterborough**
- **Family Voice Peterborough**

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