



healthwatch York

Wheelchair Services in York:

Learning from People's Experiences









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We must also thank everyone who took time to share their story with us. As one carer movingly told us "My life is complicated. I am too busy to be here. But if I'm not, who will be?" We are very grateful to every person who makes difficult choices to be able to speak to us.

Finally, we must acknowledge Kieren Hussell, currently a student at York St John University. He wrote this report for us, and contributed not just his time but his energy, enthusiasm and desire to help people into putting this report together. It was great having you with us, Kieren. Thank you.



York's wheelchair service - learning from people's experiences

Introduction

People use wheelchairs for many different reasons. Wheelchairs should be enabling and mobilising, like cars or bicycles. They are a piece of equipment to aid everyday living.

Wheelchairs constantly need to be adapted to comfortably accommodate their users. This is because, as we all do, wheelchair users change over time. Some have fluctuating or degenerative conditions that impact on their posture or weight. Children who use wheelchairs grow. These changes can lead to individuals becoming uncomfortable in their chairs.

If a wheelchair user spends long period of time in an ill fitting chair then there may be serious health risks, including posture-related complications like poor breathing or dysphasia, falls, pressure sores, and several other conditions (Wicky & Zanni, 2007ⁱ).

The purpose of this report is to help understand people's experiences of using wheelchair services in York. It sets out the national picture for wheelchair services. It also explains what people who use wheelchairs and their carers have told us. It highlights both the issues they have faced, and their positive experiences. It aims to make clear that the way we provide wheelchair services in York is a vital issue as getting it right can have a huge impact on people's lives.

The NHS websiteⁱⁱ states:

"Many wheelchair services have a waiting list for assessment appointments, so you may have to wait several weeks after being referred to have an assessment."

This shows that the NHS nationally is aware of the long waiting times for assessment appointments. However due to the long waiting list for the



Wheelchair Centre in York, people can be waiting for months at a time. In one case, extracted from the focus group transcript (Appendix 1), a wheelchair user had to wait 8 months to be assessed.

The NHS Website also explains the importance of having a wheelchair that fits the specific needs of the individual. It places particular importance on accommodating the growth needs of children. It encourages the user to contact their wheelchair service in order to be reassessed. However many users have done this and have been waiting months at a time. This puts their child at risk of harm.

The issues with wheelchair services have been recognised at national level. A summit was held on the 27th November 2014 to discuss the way changes could be brought around within wheelchair services as a whole. Recommendations included a campaign that would help raise the profile of wheelchair services and help all those involved with wheelchair services to work collectively to make permanent positive change. The summit also outlined the changes that NHS England is undertaking. This includes the formation of The Wheelchair Leadership Alliance. This brings together representatives of all key stakeholder groups to lead a collective effort in response to this challenge.

The Wheelchair Leadership Alliance completed their own research into national wheelchair service quality and have revealed some interesting statisticsⁱⁱⁱ: Roughly 1.2 million people, the equivalent to 2% of England's population, are wheelchair users. Of these 1.2 million wheelchair users, 70% have to wait for more than three months for their new chairs. 30% have to wait over 6 months. 15%, which equals out to one hundred and eighty thousand people have to wait for a year or over. This is one hundred and eighty thousand people that have to wait a year before they get the equipment that could be vital for their mental and physical health.

Although there are no official statistics for wheelchair users in York, there is an estimated figure of 3,785 people (Perry, 2015^{iv}). This means that potentially 3,785 people are at risk of health complications if they do not have access to good wheelchair services. A poor fitting wheelchair can have severe negative physical and mental effects on wheelchair users as highlighted nationally;



"This girl was in severe pain, severe discomfort and this was the only seating that she had and she was expected to sit in this all day, every day, yet this wasn't regarded as an urgent referral for priority seating."

-Kate Hallet, Senior Mobility Therapist, Whizz-Kidz^v

There are wider financial ramifications to consider too. Up to half of all people who use a wheelchair will develop a pressure ulcer at some point during their life caused, in part, by ill-fitting or ill-equipped chairs. The cost of treating the worst cases of a pressure ulcer can be as much as 16 total hip replacements. Incorrect equipment is being supplied as well as long delays in supplying the right equipment. This all costs money. For every 182 wheelchair users not able to work, the benefits bill can increase by up to £1 million. However when in work the positive economic contribution can be up to £4.7 million. By making longer term investments to prevent pressure ulcers and other related issues, money will be saved in the long run. ^{vi}

There has been more interest in wheelchair services in general around England and more research into improvements are being conducted by groups such as The Wheelchair Leadership Alliance, NHS England and the six wheelchair services improvement work streams. Although improvements are trying to be brought forwards by these groups, York is still in need of these improvements within the wheelchair service as there are people in York who spoke with us during this survey work. They believe that they are risking their health by having ill-fitting chairs or incorrect parts. However recommendations have been made in other sectors that have encouraged improvements to be made.

In order to try and help the wheelchair service in York improve, a range of possible recommendations that could be used to resolve these issues have also been suggested to help York's service provide a more efficient process for wheelchair users.



Why is Healthwatch York looking at the wheelchair service?

Healthwatch York was asked to look at this issue following the Health Overview and Scrutiny Committee (HOSC) meeting on Wednesday the 18th of February, 2015. A member of the public, with first hand experience of using the Wheelchair centre registered to speak and voiced concerns about wheelchair services in York. Healthwatch York was asked to find out more about people's experiences of the wheelchair service in York and feed this back to the HOSC. Healthwatch York had already been alerted to concerns about wheelchair services in York via comments on social media sites, mainly facebook. These highlighted issues such as waiting times for reassessment and delivery of new chairs;

"Would be great if they understood that having a wheelchair is essential for my daughters health and well being, that's why it can be so frustrating when there are delays and lack of communication"

"Months in total to get a chair, ring everyday to argue"

"My child was assessed by York Wheelchair centre, October 2014, told 3-6 weeks, phoned last week, December 2014, was told another 6-8 weeks due to it just being put in the beginning of December."

However people also had positive things to say about the staff such as:

"Can't fault the staff and the lady who measured our daughter. 🙁 funding sucks."

"Their hands are tied. They were very helpful in providing a buggy loan in between a new chair being provided for our son."

"Staff are fab; feel a bit sorry for them really"

Healthwatch York also spoke with a parent of a wheelchair user. She contacted us about a collective group of parents who all felt unhappy with the service that was provided. We made contact with this group to publicise our planned work following the HOSC meeting.



What we did to find out more

We used a range of methods to gather information about wheelchair users experiences of the service in York. We spoke with a relatively small sample, with we believe just over 30 individuals sharing their experiences. However, these included a range of wheelchair users including those with more complex requirements.

The first of these were focus groups on the 20th of April at West Offices (See Appendix 1 for the transcript of the focus group). At these meetings anyone with experiences of the wheelchair service, including those who are wheelchair users themselves or those who care for someone who is a wheelchair user, could come and give feedback about their individual experiences when using Wheelchair Services in York.

These focus groups were promoted by using a leaflet (Appendix 2) that was distributed around York by Healthwatch York volunteers and partner organisations for Healthwatch York. The Wheelchair Centre was aware of these focus groups. They were informed they were welcome to attend as observers, but felt this might inhibit discussion.

In the first focus group 10 wheelchair users attended. 4 members of Healthwatch York facilitated discussion and took notes on the wheelchair user's detailed experiences of wheelchair services.

Those who attended the focus group were first asked about the process of referral to the wheelchair centre, which prompted both positive and negative accounts of people experiences. Other key areas that were focussed on were positives of their experiences, the feeling of personalisation of their wheelchair and how they felt about follow ups of the Wheelchair Centre.

The second focus group was attended by representatives of Vale of York Clinical Commissioning Group, (VOYCCG) and York Older People's Assembly (YOPA).

Another way that wheelchair user's experiences of the wheelchair service in York were collected was through the use of a survey carried out by Healthwatch York. This survey sought to find out people's experiences when using the Wheelchair Centre in York (Appendix 4).



The questions were both closed and open ended so participants could give a more detailed account of their experience.

This survey was shared with a range of partners including;

- York Wheelchair Centre
- York Inspirational Kids
- York Independent Living Network
- CANDI
- York Older People's Assembly
- The Voluntary and Community Sector Reference Group for organisations working with older people and people with long term conditions, and;
- NHS Vale of York Clinical Commissioning Group (CCG).

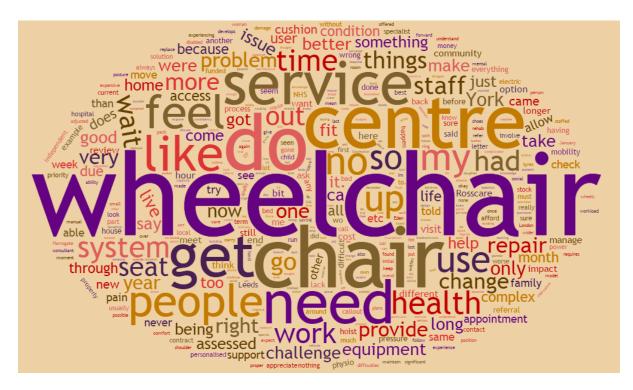
NHS Vale of York CCG also kindly distributed it to all local care homes.

We also had a one to one conversation with the parent of a child who has complex health issues. Although the wheelchair user couldn't attend herself, her parent and carer outlined them on her behalf (See Appendix 5 for the full account of her wheelchair experience).

All participants were reassured that their feedback would be given anonymously.



What we found out



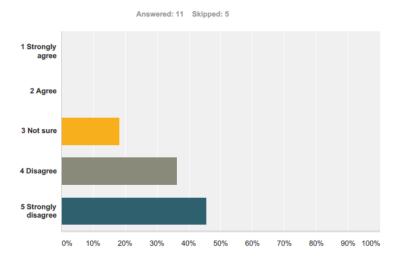
The survey responses mostly provided feedback on the Wheelchair Centre, and the common themes were identified.

- The main issue that was immediately apparent was the long waiting times in between chairs. Those who seemed especially frustrated with the service were those with children who used wheelchairs, as their health is more at risk due to their changing needs.
- Staff members are perceived as working their hardest to help, but are limited in what they can do by funding. However staff still find ways to help even with lack of funding, such as providing a buggy loan in the long waiting times between new chairs being provided.



Responses from a few key questions have been identified with the survey. Responses shown below highlight some of the important issues within the service:

Figure 1 shows the percentage of participants who agreed with the statement "If a friend needed similar help, I would recommend the service". None agreed with the statement, and over 80% either disagreed or strongly disagreed with the statement, showing that the majority of participants think that the service is so poor that they would not recommend it.



Responses

Figure 1:

Q16 If a friend needed similar help, I would recommend the service

1 St	rongly agree	0.00%	0
2 Ag	gree	0.00%	0
3 No	ot sure	18.18%	2
4 Disagree		36.36%	4
5 St	5 Strongly disagree 45.45%		5
otal			11
I.	Comments		Date
	Too time consuming if they need a chair straight away.		4/29/2015 12:35 PM
	I certainly would NOT recommend the service - it isn't a service any	/more.	4/27/2015 5:56 PM

Answer Choices



Figure 2 shows how participants felt they were treated by those who saw them. While only around 27% felt they had not been treated well, 63.63% agreed with the statement, showing that the majority felt they were treated well by the staff that saw them.

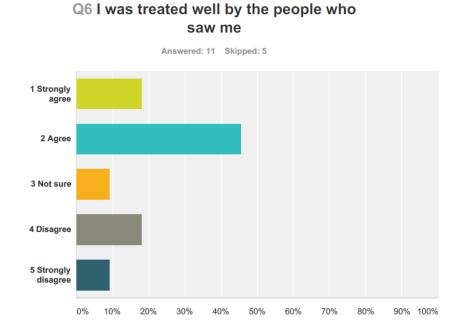


Figure 2:

Answer Choices	Responses
1 Strongly agree	18.18% 2
2 Agree	45.45% 5
3 Not sure	9.09% 1
4 Disagree	18.18% 2
5 Strongly disagree	9.09% 1
Total	11



Figure 3 show whether participants thought that their needs were taken seriously. 63% weren't sure if their needs were taken seriously or not. Only 27% agreed that there needs were taken seriously. This shows that the participants who use the service are not being reassured that their needs are being taken seriously.

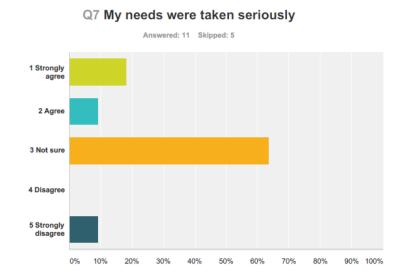


Figure 3:

Answer	Choices	Responses		
1 St	rongly agree	18.18%		2
2 Ag	ree	9.09%		1
3 Not sure		63.64%		7
4 Disagree		0.00%		0
5 St	5 Strongly disagree 9.09%			1
Total				11
#	Comments		Date	
1	The whole process is time consuming and there is no sense of urgency event though if	you don't get sorted your	4/29/2015 12:08 PM	

1	The whole process is time consuming and there is no sense of urgency event though if you don't get sorted your body and way of life will deteriorate	4/29/2015 12:08 PM
2	If our needs had been taken seriously, we might have ended up with the chair we need and not the one the wheelchair service "want us to have."	4/27/2015 4:19 PM



The focus groups also identified similar common themes to the surveys, as well as other issues which included;

- The waiting times for new chairs was again brought up, with added stress on children and those with degenerative conditions who spend most of their time in their chairs.
- Poor equipment such as seats, were also an issue as they have reportedly led to health complications such as pressure sores, fatigue, forced bed rest and mental health issues (specifically depression).
- With Ross Care now handling all the repairs, many people's experiences has found them less efficient than when the repairs were carried out by the Wheelchair Centre.
- Although it was agreed in the focus groups that the staff were trying their best, it was suggested that they are restricted so much in what they can do due to a faulty system that didn't allow them to work at their best.

There have also been issues raised by wheelchair users relating to specific areas of York. These were brought to the attention of Healthwatch York during a volunteer monthly meeting, where feedback was given that had been left by members of public to specific volunteers. Electrical powered chairs have to be charged for periods of time before they can be used. This is the also the case for hoists in disabled bathrooms to help wheelchair users manoeuvre themselves within the bathroom. However in the same building within York Library, not only was the wheelchair that was offered for hire not charged, but nor was the hoist in the bathroom. This meant that the wheelchair users in the library had to charge these themselves before using them, which should not be their responsibility.

Finally the one to one with a parent of a wheelchair user was also used to illustrate an individual's experience (Pseudonym used). The issues raised here were similar to those raised in the focus groups and the surveys, with the biggest concern being the waiting time between new chairs and/equipment for repairs. However there were



more specific negative feelings that were expressed in this one to one, such as "Emily's" feelings about her wheelchair and her disability:

"When my chair works, I don't feel disabled. At the moment, I've never felt so disabled in my life. It's because of pain, posture. I hate being disabled at the moment because of my wheelchair."

It's clear to see how the right wheelchair can have a major impact on the lives of wheelchair users. For some, they can be in them for most, if not all, of the day, every day. Therefore, as well be a serious health risk, an ill-fitting wheelchair can add stress as well, whereas an efficient wheelchair can have a positive impact on wheelchair users lives.



Issues associated with the current repair provider (Ross Care)

The repair service in York was recently tendered. This means Ross Care now complete all repairs. It is believed that the aim of the tender was to improve the service for wheelchair users. However this has had the opposite effect. Many users feel that the service in both companies has now become less efficient. The key messages about this service were taken from the focus groups. The majority of issues associated with the repair system were new, but there was also a feeling some older issues have become exaggerated due to the new provider. These issues included:

- Less responsive and less proactive call outs with only repairs that had been documented previously being completed, ignoring maintenance repairs that had occurred between the documented repair needed and the callout.
- A belief that there is reduced capacity within the Wheelchair Centre, the original provider of wheelchair repair service in York, leading to an increase in the already long waiting times for new wheelchairs or equipment. The Wheelchair Centre state that there has not been a reduction in the capacity of the Wheelchair Assessment Service.
- A belief that there is reduced flexibility of repair appointments that wheelchair users can make. Individuals reported that call outs can now only be to home, whereas previously they could be called out to work as well. The Wheelchair Centre state that call outs can be made to work, or in the case of a child, to school
- A limitation in accessing the correct stock parts needed for repairs.
- Communication between the two services providers is seen as poor, which has led to feelings of frustration among wheelchair users. The Wheelchair Centre and Ross Care state that they both have access to the same computerised record system, BEST, so this should not be the case.

All of those who attended the focus groups agreed that they preferred it when the repair service was still in York.



Issues associated with the wheelchair service

There are issues that seem to be apparent about the wheelchair service in York that have been ongoing even before Ross Care started handling all repairs. Although, with reported poor communication between the two, some ongoing issues appear to have recently deteriorated. (The key messages from wheelchair group can be found in the appendices.)

- It is clear that lengthy waiting times have always been an issue. However, waiting times have been further increased. People using the service believe this is due to reduced capacity at the wheelchair service provider in York following the change to the repair service
- Many focus group attendees were specifically worried about the waiting times for children. Because of the long waiting times to order new chairs or replacement parts for repairs the child has often grown so much that more equipment is already needed. Strong concerns were also raised about the health of the children that were struggling with their out of date chairs as they were too small for them to function properly which would leave the child at risk.
- Delayed communication between the Wheelchair Centre and wheelchair users was an issue that has had a number of impacts; along with the long waiting times, lack of communication has left wheelchair users feeling neglected and frustrated. People felt that better communication would also help the service assess if any equipments needed replacement parts or any other maintenance before a call out.
- Many staff in the Wheelchair Centre were found to be positive and as helpful as they could be, particularly Mike Edwards. However, staffing arrangements make it increasingly difficult to communicate with wheelchair users who had already given information about what they needed to another member of staff.
- People felt that the Wheelchair Centre does not reflect the move to personalisation. Wheelchair users feel frustrated that they have to research new options themselves. They are told what they are allowed to have without the opportunity to explore other options. There was a specific frustration around the restrictions applied to



determining who is eligible for an electric wheelchair, without a wider consideration of the long term impact on health, independence and economic wellbeing.

• A specific concern was raised about the range of suppliers the Centre uses. Some people stated that more cost effective options are available using a wider range of suppliers.



Conclusion

The majority of respondents with experience of York's wheelchair service feel improvements can be made. Excluding the common theme of the staff in the service trying to do the best that they can, and treating those that use the service with care and respect, the rest of the experiences that most people shared were negative, for a variety of reasons.

Within the survey, Healthwatch York asked how much people agreed with the following statement:

"If a friend needed similar help, I would recommend the service"

11 people responded. 5 individuals skipped the question, having provided details of their experiences earlier in the survey. 0% agreed with the statement, 18.18% weren't sure, 36.36% disagreed and 45.45% strongly disagreed with this statement. These answers clearly demonstrate high levels of dissatisfaction with wheelchair services locally amongst respondents. This contrasts with the Friends and Family test feedback gathered by the Wheelchair Centre throughout 2014, where a majority responded positively.

In the NHS standard contract for complex disability equipment: environmental controls, section 2 (aims and objectives of service) a number of aims and objectives are outlined including:

• To participate with the provision of other EAT (Environment Action Teams) such as communication aids, powered wheelchair controls and other equipment of daily living, where this is appropriate.

• To collaborate with other clinical services and social agencies to optimise patient's wellbeing.

• To ensure that patients and carers are well informed on the use of the equipment that has been loaned to them.

• To adapt equipment provision to meet the changing needs of the patient.



• To provide the service in an independent, unbiased, cost effective and accountable way.

• To ensure all staff within the service are trained to an adequate and relevant level of competency, including awareness of technological developments

It is clear from the responses we received that a number of people in York believe that our wheelchair service does not meet these aims. Wheelchair users have a right to a service which doesn't put their health at risk because of the delayed times between re-assessment and getting a new chair fitted.

In 2011 a paper by the National Wheelchair Managers Forum^{vii} was released in response to documents published by the All Party Parliamentary Group (APPG) for Paediatric Wheelchair Reform. The APPG recommended extending patient choice by implementing a system called Any Qualified Provider (AQP). The National Wheelchair Managers Forum paper expressed concerns about the impact of further fragmenting of wheelchair services. These concerns are reflected in people's experiences locally, who feel that the splitting of the service into assessment and repairs has had a negative impact on them. The service also had concerns about AQP further fragmenting the wheelchair services. They were relieved when AQP was not implemented locally for wheelchair services by NHS North Yorkshire & York Primary Care Trust.

This research shows that the wheelchair users in York are not alone in the area of having to complete their own research to find new developments and other options that are available to them. However whereas steps have been taken to improve the wheelchair users access to other options and new developments, York is still in need of this to improve its wheelchair service.

Recommendations can be made based on the information that Healthwatch York has obtained. When wheelchair users that were part of the survey group were asked;

"If you could change one thing about this service what would it be?"

A range of answers were given including;



"We wish the service was full time with more staff. Less waiting times especially to update our wheelchair. An annual or biannual review of needs would be very helpful"

"To be able to convince the decision-makers who have changed the way this service operates that things need re-thinking"

"The time it takes from referral to getting the equipment"

"They listen to you as the carer as they are the people who know the needs of the wheelchair user, they live with the problem 24/7 the staff do not"

These answers show a section of what the wheelchair users feel should be the highest priority of improvements that are needed within York's wheelchair service. These can be edited into realistic suggestions that could be considered for improving these areas of service.

In March 2010 an "Enter & View" visit was conducted by York LINk (predecessor of Healthwatch York) to discover more about the issues that had been reported related to wheelchairs. The main conclusion of the report outlined that the Wheelchair Centre was well run and with only a few small adjustments could provide an excellent service. Some of the recommendations were similar to the ones that are still relevant now, such as developing newsletter highlighting local news as well as new options and developments and the need to improve communication between client and customer.

However since 2010, new issues have become apparent that may need to be prioritised above issues that are still outstanding. This includes some of the recommendations outlined below that can have serious health complications if they are not resolved.



Recommendations

Recommendation	Recommended to
Review ideas to increase the sense of belonging	NHS Vale of York
 among wheelchair users. When people feel more informed, they are more likely to be satisfied with the changes that are occurring. In order to increase the sense of belonging, many wheelchair users suggested options that they think could be applied. These include: Provide wheelchair users with regular follow ups to ensure that equipment was still needed and fit for purpose. 'MOT's' or annual checks were favourite ideas of the focus groups. Develop a newsletter highlighting local news as well as new options and developments. Develop a service user group which can be used to help design, deliver and review services, and share new developments, as well as providing peer support. This should link with existing peer support networks such as CANDI, York Independent Living Network, 	Clinical Commissioning Group.
and York Inspirational Kids Review the eligibility criteria for electric wheelchairs, Consider in particular conditions such as ME / CFS and MS.	NHS Vale of York Clinical Commissioning Group.
Review methods to improve communication between the 2 providers to improve access to relevant information, increasing call out efficiency and productivity,	NHS Vale of York Clinical Commissioning Group.
Consider encouraging staff to have more of a say in how wheelchair services in York are run. This may allow them to perform at their best without being as limited by what they can do, and help build better relationships with the wheelchair users.	NHS Vale of York Clinical Commissioning Group.



Consider implementing a system that would allow staff to prioritise children or those with degenerative conditions, to allow for their continually changing needs.	NHS Vale of York Clinical Commissioning Group.
Longer term, consider reviewing the pathway for wheelchair service provision, working alongside existing service users. This should also consider the changes to Community Services through the transformation agenda, the impact of personal health budgets for people with long term conditions, and the impact of separating out the wheelchair repair service from the contract to provide wheelchairs.	NHS Vale of York Clinical Commissioning Group.



Appendices

Appendix 1 – Focus group meeting transcript from the 20th of April.

Wheelchair services Focus Group 20.04.15

For the purpose of confidentiality only the genders of people will remain in the transcript, identified by M for male or F for female.

Attendees

2 Healthwatch staff 2 Healthwatch volunteers 10 people who use, or support someone who uses, the Centre

Introduction

It was explained to the group why Healthwatch has been asked to look into people's experiences following questions to the Health Overview and Scrutiny Committee. All feedback will be used in a report to the committee.

The importance to have a contact group was emphasised by a member of the focus group as it was said it was very difficult to make a difference alone.

The process of referral to the wheelchair centre

M - has been done in 2 different ways.

1 self referral when feel chair, usually due to seat, doesn't meet needs. Ring the centre, say need to be seen to discuss options.

2 referral by health professional, usually a physio or GP.

F – Straight forward referrals for car controls.

F – Easy to get to the wheelchair centre.

F – Hard to get through on the phone. Staff are part time. There is not someone there all the time. You have to leave a message. Usually takes a week. Sorting a cushion out, it took a while to speak to someone. To get a new chair takes 8-12 months. It takes 8 months to get assessed. Need to get an assessment. They are very nice people, but the system is against them. It feels like wheelchair services are not a high priority locally. It's run on a shoestring.

F – Repairs have moved to Leeds. Have rung them and they do come out. Repairs through Ross Care are okay.

F – are there now 3 strands – repairs, in Leeds, adjustments here in York, and new chairs, which are also here?



M – getting past the receptionist at the Wheelchair Centre is a challenge. Has been 8 months to get a first assessment. From then, with complex seating, it can be another year.

M – I've been waiting about 4 years. Referred about my car initially. Couldn't easily get my wheelchair over my shoulder due to damage to the shoulder. Since first needing a wheelchair in 1982 I have never had an NHS chair. Always bought my own. Wish I had again. Vycare cushions – took 2 years to get a cushion. Wheelchair chap came from Gerald Simmonds. Don't get on with the chair. Mike Edwards had to make the chair better. Used to have an Etac chair. It's been a long process and it's still not right now. It's been a horrible experience. Because of the weakness in arms, really struggle with it. It is important that people from the Wheelchair Centre see how you live, how your house is set up. My house is designed for smooth transfers. But the wheelchair wasn't right to fit with everything else.

Bought EasyMotion wheels. These were £1,000 cheaper through a site run by a fellow wheelchair user than from Gerald Simmonds. They are a very expensive option. These wheels have made it possible for me to do more, got me out and about. **(Staff Member)** at the Wheelchair Centre says you can only have a manual or a power chair. If you can use your arms you are not allowed a power chair. If you can self propel you have to. There are no questions about the extent of this.

F – person I work with who has ME is not allowed a power chair but has issues with fatigue, so Wheelchair Centre is not supportive of her needs. M – damage to shoulders may be due to overdoing things in the manual wheelchair. Rehab is all about sport, pushing limbs too far, and can mean you up with less mobility overall.

F – none of this (things like the EasyMotion wheels) comes out through the Wheelchair Centre. They don't encourage you to think of new options. They don't keep up to date with developments.

F – for people who use wheelchairs, they are like your shoes. But you are not allowed e.g. outdoor and indoor shoes, just 1 chair for everything.

M – is a lot about money. But we use expensive chairs. Need to be more discriminating. Need to help people explore options.

F – not that knowledgeable about different conditions and variations within conditions

M – With degenerative conditions your needs will change within 2 years, so you need regular seating assessments. Due to the lengthy wait for equipment, by the time you get your seat it's no good for you. So you never get a seat that works. Was the same as a child – in 2 years you have grown and the chair is no good. At University in Newcastle, the



service was much better. If you needed adjustments these happened quickly. Other NHS services do things at a similar speed to the Priory Centre (a private provider).

F – It is not the norm to have to wait 8 months. York is out of line with other areas.

F – staffing has reduced, it's now a part time service. People are only available at certain times

M – at the wheelchair centre, I don't think I've ever seen another wheelchair user there. There is never anyone else waiting.

M – lots of staff at reception area. Physio contact reception to contact service user to check that appointment is okay who then contact physio to confirm or have to rearrange if not okay. Not very slick.

F – we've never been offered a home visit. Repair people do come to the home though. And Mike Edwards is very good.

M – most of the staff are good. The building capacity is there, with 2 assessment rooms and a waiting room. But the staffing isn't. We are told that the amount of OTs is not sufficient. But if this is true, has this been flagged up to commissioners to highlight the problems this is causing and say we need OTs, technicians etc. Never seen both rooms at the centre in use. Last time I called they could not say how long I would wait as 1 consultant was off on long term sick.

F – lost half their work with the change to contracting and the repair side gone, but this hasn't created extra capacity. What happened there?
M – Commissioning complexity, with the involvement of Harrogate Foundation Trust in a York based service is unhelpful.

F – GPs don't know where to advise you to go, or what you are entitled to. Is the service waiting time as long as it is to encourage those who can afford to will go private, saving the NHS money? That's what it feels like.

M – a lot of people who use wheelchairs are going to be hard to reach to allow Health OSC and the CCG to hear their views. Those in homes, those in special education, will be experiencing the same things and need to be heard too.

F – if you have the wrong chair cushion you will get pressure sores. You can end up in hospital.

M – you have to live with pain. You're in seating that pushes you round the NHS system. Properly fitted wheelchairs could stop so many other health challenges.

F – you are often in your wheelchair from getting up in the morning to going to bed. It is vital that your chair is right.

F – if you were in work for only 8 hours a day in a poor fitting chair, health and safety law means you'd need to do something about it. But



for wheelchair users in a chair you are in from dawn till dusk there isn't the same sense of urgency.

F – you are lucky if you can transfer.

F – you can't afford to wait if your chair isn't right.

F – We've had issues with cushions, the wrong ones supplied, too thick, too thin, and then you are back to the start with fixing the problem. Pressure sores have such a serious impact on ability to live.

M – must be something majorly wrong if these challenges are happening. Would like to see extra funding – gone on too long. They need to work with wheelchair users.

F – outsourcing repairs is non-sensical. Often have punctures, splits etc. When the service was based in York, I used to ring up and say, for example, "My caster is jammed, can I bob in?" I would get it mended in half an hour. Now there are no spare nuts and bolts. The Wheelchair Centre don't do any repairs. They don't carry stock, tools or equipment. M – all mechanical stuff now with Ross Care. I've had 3 callouts. The first one, the engineer came out and said "Oh right, one of those is it? They didn't tell me what sort of chair it is, I've got nothing in my bag for that." When the service changed, the Wheelchair Centre does not appear to have supplied any details about which chairs people have to the new provider. 2nd callout, there was a seating problem. Rosscare came out to mend the chair, but wasn't clear what triggered the callout. Asked what they were mending and was told they had brought a fluid pack. Engineer came and said he wasn't sure what the pack was supposed to do so he'd send a physio. I still have the pack but it has never been fitted.

3rd time – didn't come for the morning appointment as booked. I had an afternoon meeting so had to cancel the callout.

F – Now that it is two separate services it is more difficult. There used to be regular staff, who knew you and your chair. It was Jim or whoever. They used to be proactive – if they came to do your castor but spotted that the brake was going, they'd tackle that within the same visit. Now, they are only able to do what's on their job sheet. If you spot something else during their visit you still have to put another job in as they are not allowed to sort it. Before, they used to be proud of their work, and get to know you. They could use their initiative.

F – they no longer know you and your equipment. So they come out and say "Oh, it's the wrong size."

F – they don't have any information about your chair. But the Wheelchair Centre has reams and reams of it. The systems don't talk to each other. The service in York doesn't talk to the service in Leeds, and vice versa.



F – appreciate there are no universal fittings, so difficult to carry everything. Services are limited on stock.

F – straw poll, which is better – old repair system or new?

Unanimous vote – all thought it was better before the change.

M – Rosscare have an enormous contract across most of the North. F – much more restrictive set up for people who work. They won't give you a time. Before they would say we'll be with you during a particular hour slot, or would call and say "Go to work, we're running late so we'll meet up with you there." Now it feels like you are not a priority.

F – people don't see wheelchair use as a health issue. But it is. If you slip up you end up in hospital. If you get sores you end up in hospital. It feels like a tired system, not a 21st Century one. It feels like you are not a priority. But anybody can end up in a wheelchair.

M – feels like they see this just as something that enables you to go out. They forget about health and safety. Failure to get this right can have very serious consequences, but it is not treated as something that carries significant health risks. It's not the same as getting a repair from BT, it's a health isssue

F – there are mental health implications too.

F – You need to go out and interact with people. But it's more than that – a wheelchair is an essential tool to help you live. It feels like at the moment they are doing you a favour giving you a wheelchair.
M – had a problem in London. Ended up getting very expensive health rehab. This can happen, and has significant costs attached.

M – how do we persuade the CCG to address this? How do we demonstrate the impact of properly funding this? E.g. reduction in mental ill health, pressure sores. What are the cost savings of getting this right? M – how do our costs compare with Nordic countries? How do we measure the wider societal impact? For example, being able to work because you are not in pain, not having to take bed rest etc.

F - 1 woman was waiting for a seatbelt last year. She fell 3 times in the bathroom. On one of these occasions, she fell and got covered in bleach. She ended up with bad bleach burns all over her body, causing significant pain and needing substantial treatment. But she's still waiting for her seatbelt.

M-I had a problem with a cushion not being velcroed. I had an accident in the toilet where my leg got stuck. I ended up bleeding. At that point they came out for a home visit, in response to a list of all the faults with the chair.

F – home visits would be ideal – to understand how I get in my car, how our garage works, where my sink is. They are not making good use of



the existing location at the wheelchair centre. Can the space be better used?

F – they do have bits and pieces.

F - I tried this chair there and it worked for me. They also replaced my cushion when it was lost whilst on holiday free of charge.

M – there are no problems with stock or cushions where they are standard items. They have a big warehouse. But there are more challenges where requests are more complicated. There are certain skills that the current team don't have, such as moulded seats and autoblock. A specialist then has to come out. It usually requires several visits to do what's needed. If lots of people need these then it is no wonder it takes so long.

There is a clinic at special schools once a week, but for wheelchair users in mainstream schools it's not so easy and everything takes longer.

Good things

F – good staff who try their best, but get the feeling they're a bit low too. It's just the waiting. No nuances in the system for how complicated your chair is. They are under pressure.

M – when it came to the home visit they were very helpful.

M – it's the system not the people. I remember that they gave me a seat to go abroad. They do try. It's because of wider issues. The time it takes to get seating from the initial call, not just the consultation, is so long. That's the problem. It feels like the problem sits higher than the Wheelchair Centre staff.

F – I don't feel that the Wheelchair Centre staff have been involved in the changes. People using the service have not been engaged in decisions. When the repairs service moved I just received a very factual letter –3-4 weeks notice, if that, that the service has been changed. There was no chance for any discussion.

F - I got a letter saying repairs are now in Leeds. I think the service should be somewhere we can get to. People like things local and accessible.

M – there's a wider issue. There is a lack of London style cabs in York – Fleetways does have them but only 3. So you need a van to get to the centre. There's a card in London that allows wheelchair users to go anywhere for £3 in a taxi. But there's nothing like that in York, so getting to the Wheelchair Centre is a nightmare for me.

York generally has issues with accessibility – lighting, pavement condition. I like what has been done in King's Square. It's very accessible. It proves what can be done. The level access is beautifully done.



F – things are improving for wheelchair users in York, I just wish the Wheelchair Centre would keep up.

Personalisation – where is the Wheelchair Centre on the personalisation journey?

F – they try and tell you there is no choice where your needs are more complex. Because manufacturers change models, the Wheelchair Centre don't seem to appreciate the difference these small changes can make to being able to use existing equipment. For example, I have a hoist, which cost thousands of pounds. Small changes to wheelchair design, an inch here or there, can mean that the chair won't work with my hoist. It must be possible to adapt chairs to continue to meet the specification of the hoist.

Recently I was told that solid tyres were my only option. But they are really uncomfortable. The centre didn't take my condition into account. I was told I couldn't have other tyres on that chair. I checked the website, found them, and emailed the wheelchair centre. There is a small cost saving in providing solid tyres as there are no punctures. But there are massive health implications, as they do not absorb shock, increasing damage to bones, worsening a bad back, etc.

M – I had to remodel my house due to a chair. There's no joined up thinking. I was going to have a particular type of chair but I realised it wouldn't fit in my vehicle as it would be too high. Need better understanding of how you live to understand best options.

F – assessment doesn't start with you, where you live, your lifestyle, your vehicle, if you work. It's not for them to decide what you should have.

Follow up

F – there is none. Once you've got the wheelchair, that's it.

F – would be good if the centre called once a year to check how things are.

F – you don't 'belong' to the service. They leave you to it.

M – if they had annual or six monthly check ups, you'd already be in the system. Rather than waiting to get into the system.

F – should be like dentists, a fall-back position with routine follow ups.

F – some people do get better, may have a wheelchair they no longer use, so could free up stock too.

F – you do feel like a nuisance when you try to access the service because something has gone wrong

F – yes, because you usually refer yourself



M – asking for a seat. Thought letters from physios, consultants etc, would move things forward as they used to. But this doesn't seem to be working now. There is still no appointment but I've been chasing since January. I don't feel they have a clear grasp on it. They don't seem to know how long their waiting list is

F - it feels like the centre is slowly disappearing.

F – there should definitely be something like an MOT.

M – Some people face difficulties in communicating. How are we reviewing their experience of the wheelchair centre, making sure they are not living in pain and discomfort? Without regular reviews we will only address issues once there is clearly a problem, for example a pressure sore develops, by which time it's too late.

F – when they changed make and model and there were issues with the hoist, Mike Edwards got an Invercare rep to come and see the hoist, check the dimensions. He got authorisation to move bits around. It was all to do with the rope and the balance. Rep came out, understood the problem. It was Mike's suggestion. He's Assessment Manager and he's very good.

F – the main issues are that we want the Wheelchair Centre open for longer hours, properly funded and staffed, with a drop-in repair centre. Currently I feel that the service has gone backwards.

M – I would like to work with them, to improve things. We can explain the challenges, and help explore solutions.

There was widespread agreement that ongoing involvement of a group of people using the services could help improve things going forward.



Appendix 2 – Flyer advertising the focus group on the 20th of April.





Appendix 3- Key messages from the focus group

Key messages from the wheelchair service focus groups held on April 20th 2015

1. Most people report that waiting times for new chairs are too long. This is particularly true for children and young people, whose bodies are still growing, and for people with complex needs and people with degenerative conditions who spend a lot of time in their chairs. It takes time to get through to speak with someone, then takes time to get an assessment, and then there are further long waiting times for new chairs.

2. A number of people with complex seating needs stated that ongoing problems with poor seating were resulting in health complications. These include pressure sores, fatigue, forced bed rest, and mental health issues, particularly depression.

3. Splitting out the service, with Ross Care now handling all repairs, has had a detrimental impact in a number of ways:

- Less responsive / proactive repair service where they will only manage the repair on their worksheet, not any other problems which have presented since
- Reduced capacity within the Wheelchair Centre overall resulting in increased waiting times
- Communication problems between the two services
- Reduced flexibility of repair appointments with only morning or afternoon slots available to your home (previously could get them at work too)
- Reduced access to stock parts through both aspects of the services

All attendees at the focus group stated they preferred it when the repairs service was still in York.

4. People have questions and concerns around whether the facilities are being used to best effect. There is the perception all staff are part time, there are not enough staff, and people using the service report usually being the only person there except the staff.



5. Staff at the Wheelchair Centre were perceived to be trying their best within an inadequate system. Many reported how lovely the staff were. Particularly singled out for praise was Mike Edwards.

6. Engagement and communication with people who use the service has been poor. There is no service user group, nor do they feel actively engaged with when changes have been made.

7. There was a strong feeling that the centre does not reflect the move to personalisation. Options are restricted, people reported having to do their own research to find out about new developments or equipment, and are told what they are allowed to have. There was particular concern around the restrictions on being provided with an electric wheelchair. If you are able to move a chair around at home using your arms you do not seem to be eligible for an electric wheelchair. People with ME / CFS and MS have all reported that this impacts on their ability to live a normal life.

8. Many users feel that the service would greatly improve if people felt a sense of belonging, and that there was regular follow up, as you'd expect in other health services like dentists and opticians. Frequently mooted was the idea of an MOT or annual check, to make sure equipment was still needed and fit for purpose. Other ideas included a user group, and newsletters highlighting local news and developments in wheelchair technology.



Appendix 4- Survey used. Wheelchair services in York

Introduction

Healthwatch York aims to put you at the heart of health and social care services in our city. We want to gather feedback from as many people as possible. By getting feedback on your experiences we can see

We have been asked by City of York Council's Health Overview and Scrutiny Committee to look at wheelchair services. Have you or a member of your family used wheelchair services what is working well and what needs to be improved in York within the past 2 years? If so, we'd love to hear more about your experiences, both good and bad.

Our survey is anonymous and we will not publish any information to identify you. The findings of our survey will be presented to the Health Overview & Scrutiny Committee - this committee is responsible for overseeing how well health and care are being delivered in York.

Thank you for taking part in our survey. Together we can make York better!

1. Are you:

□ A young person under 18 who uses wheelchair services?

A parent or carer of a young person between 11 and 18 years old who uses wheelchair services?

An adult who uses wheelchair services

An adult who cares for someone who uses wheelchair services

A young carer for someone who uses wheelchair services

Other (pleases specify):



Note for carers:

All questions are written as if you are the person using the service. For carers please read them as saying "or the person you care for".

2. When did you access the wheelchair service?

 \Box Within the past 6 months

□ Within the past year

□ Within the past 18 months

 \Box Within the past 2 years

 \Box Over 2 years ago

3. How easy was it to get help from the wheelchair service?

4. What has your experience of the wheelchair service been like?



5. Please read the following statements and tell us whether you agree with them or not:

a. I feel that the people who have seen me listened to me:

□ Strongly agree
Agree
□ Not sure
Disagree
Strongly disagree
Comments:
h. I was treated well by the people who saw me:

b. I was treated well by the people who saw me:

□ Strongly agree
Agree
□ Not sure
Disagree
Strongly disagree
Comments:



c. My needs were taken seriously:

□ Strongly agree	
Agree	
□ Not sure	
Disagree	
Strongly disagree	
Comments:	

d. I feel that the people in the Wheelchair Centre understand my needs:

Strongly agree
Agree
□ Not sure
Disagree
Strongly disagree
Comments:



e. I have been given enough explanation about getting the right chair or equipment:

Strongly agree
Agree
□ Not sure
Disagree
Strongly disagree
Comments:

f. I have been kept informed about when my chair will be ready:

□ Strongly agree
Agree
□ Not sure
Disagree
Strongly disagree
Comments:



g. I am involved in making decisions about my options:

Strongly agree	
Agree	
□ Not sure	
Disagree	
Strongly disagree	
Comments:	

h. The facilities at the Wheelchair Centre are comfortable:

Strongly agree
Agree
□ Not sure
Disagree
Strongly disagree
Comments:



i. I have been given enough explanation about getting the right chair or equipment:

□ Strongly agree
Agree
□ Not sure
Disagree
Strongly disagree
Comments:

j. The appointments are usually at a convenient time:

□ Strongly agree	
Agree	
□ Not sure	
Disagree	
Strongly disagree	
Comments:	



k. I am able to rearrange appointments to suit me and my family life:

□ Strongly agree	
Agree	
□ Not sure	
Disagree	
Strongly disagree	
Comments:	

I. It is easy to get to the place where the appointments are:

□ Not sure	
Disagree	
Strongly disagree	
Comments:	



m. If a friend needed similar help, I would recommend the service:

□ Strongly agree
Agree
□ Not sure
Disagree
□ Strongly disagree
Comments:

n. Overall the help I received has been good:



o. The service has made a positive difference to me:

Strongly agree
Agree
□ Not sure
Disagree
Strongly disagree
Comments:

p. I feel I have the right equipment for me:

□ Strongly agree	
Agree	
□ Not sure	
Disagree	
□ Strongly disagree	
Comments:	



6. If you could change one thing about this service what would it be?

7. How long did you have to wait from first asking for support to getting your wheelchair?

8. If you had been able to get help earlier, would this have helped?

□ Yes	🗆 No	
Comments:		



9. Were you given any information to support you in future? For example, what to do if your needs change or there are any problems with your chair?

10. Do you have any other comments you would like to make?

Please return this survey to;

Healthwatch York

15 Priory Street

York YO1 6ET

This can be sent free of charge by writing Freepost RTEG-BLES-RRYJ before the address. If you can use a stamp, this helps us save money for other Healthwatch York activities.

If you would prefer to complete this survey online please go to;

https://www.surveymonkey.com/s/YorkWheelchair



About you – Monitoring information

You do not nee helps us if you	-	y of the followir	ng questions, but i	t
11. Please tell u	is the first half of	your postcode:		
12. Your age: 36-50	□ 0-18	□19-25	□ 26-35	
80+	□ 51-60	□ 61-70	□ 71-80	
13. Do you cons	sider yourself to b	be a disabled per	rson?: 🗆 Yes	
14. How would y	you describe you	r gender?:		
15. How would y	you describe you	r ethnicity?:		
16. How would y	you describe you	r sexual orientat	ion?:	



17. How did you hear about this survey?:

18. Are you happy for us to use your comments within our report?:

Would you like to be kept informed about Healthwatch York news and activities through our quarterly newsletter? If yes, please leave your preferred contact details – either email or postal address:



Appendix 5-1 to 1 with parent

Karen, parent to Emily. (Names changed for anonymity)

Emily can't be here. Emily has complex health issues and mild learning difficulties. Her chair is her way to the world. So not being able to have the right chair is having a huge impact on her ability to live a full life. Emily says "she is unable to live her life to her full potential because of not having the correct support and seating system." She experiences physical pain constantly, and this brings with it mental health challenges. Emily needs a complex chair with a seating system.

One of the main issues is a lack of a review system. If you are complex you need a review process. There has to be a better system than the current one. There also needs to be better local access to a seating specialist. The staff do their best but are they trying to be everything to everybody?

Emily is 24. Over the years, the workload seems to have got worse. It's always been bad but now it is worse than ever.

The computer needs a review system.

The service has to look at people as individuals. The service has to be personalised and able to support people with more complex, more challenging requirements.

The answer seems to be, we can give you a voucher. Emily is used to using a power wheelchair only in safe spaces, like college and at home. She uses a manual wheelchair when out and about. She is now looking at replacing both chairs. The voucher system puts all the emphasis back on the family to research things.

The Wheelchair Centre won't interchange parts on wheelchairs either. Things might be better with a seat from one firm and a back from another, but the Wheelchair Centre won't allow it. But if we pay outside of the system no one will take responsibility for maintenance. What we need is a regional seating specialist.

Appointments – you have to wait 3 months. Then you go along and share what you've found. When you ask what the Wheelchair Centre have found the answer is nothing.

3 years on, still in the same chair they wanted to replace 3 years ago. The Wheelchair Centre keeps trying to make it right, with bits of foam. Emily said "It's not scrapheap challenge, but that's how it feels." The family are given the bits and sent away to fiddle with them rather than having them actively fitted at the centre itself.

The problems with the chair are affecting Emily's independence. She says "What would I do if you aren't here?" She can't move on with carers



as they can't get her positioned comfortably. Due to discomfort she needs to have bed rest every 2 hours. This restricts her, and the family's, ability to undertake any activities.

Emily is experiencing back pain. She has complex posture but thinks the chair is making this worse. She said "It feels like I'm on a treadmill sat in my chair."

"Life is hard enough, but it feels like this is leading to depression. If this is the future I can't leave home."

The Wheelchair Centre is not listening to what she needs. She is worried that staff don't have the same knowledge her parents do.

"I feel like a child again. I'm reliant on you as you are the only one who can get me right. I feel like the Ugly Sisters with Cinderella's slipper." How does this fit with personalisation? It's not a fit for purpose solution. "I want to be going out with my PAs but I can't take my ill fitting shoes off and swap them for comfy trainers. I have to go to bed."

"How do we support people with communication problems?" If it's this bad for people who can communicate, what difficulties are those that can't experiencing?

"What is the long term impact of not being properly supported?" The Wheelchair Centre want to mould the seat to her shape, but she wants to be able to maintain her posture and body shape as much as possible, to prevent further long term health problems. She believes that if we get this right, she will have a better quality of life, maintaining health not making it worse.

Services must enable you to maintain dignity and quality of life. It's not just about the money, it's about thinking for solutions. We've got to be more creative. The service has to move on, it must be modernised. There is a need to look at workload, to manage more complex cases. It feels like we are losing years of life. Specialists can see what is right for you. So we need reviews for these cases. Something like an annual check.

What about service and maintenance? It's not a proper service. You can't afford your chair to breakdown. Rosscare is in Leeds, which is so difficult. There is nowhere to get a minor repair. It's a difficult process.

There needs to be a fast track for people who cannot manage without a chair. It needs proper planning, you need to have plans in place for how to manage without a chair. There's no MOT system, your chair is not tested.



We have to chase the wheelchair centre. No one has looked at the chair for a long time. There's no consistency. It feels like the centre is very disorganised. It doesn't feel like there is a system. Are the staff struggling with the workload? Lack of a can-do attitude. Would like to see staff questioning the situation. If there are not enough resources to meet needs then something needs to be done.

Lost 2 months just to go and try something again.

Karen - I have used one of those mesh chair inserts you can buy for £1, for lumber support. It is helping. I pointed this out to the centre, but nothing is forthcoming from them. It feels like they can only come up with solutions they've had before. I don't feel that they are aware of the latest developments and models. The system needs to change. I don't have the energy to come here today but if none of us speak up it won't change.

Emily – "I dread going to the centre, I'm always disappointed. How much longer will I just sit in a chair?"

Karen and Emily have friends who are parents of life-limited children. And they are not prioritised. This is awful. Where life expectancy is short, the least we can do is make sure they have suitable chairs for the time they are with us, living life with dignity and comfort.

Emily – "When my chair works, I don't feel disabled. At the moment, I've never felt so disabled in my life. It's because of pain, posture. I hate being disabled at the moment because of my wheelchair.

Quote from Karen – this affects her confidence. She doesn't have the right chair to help her live.

There have also been issues raised by wheelchair users relating to specific areas of York. Electrical powered chairs have to be charged for periods of time before they can be used. This is the also the case for hoists in disabled bathrooms to help wheelchair users manoeuvre themselves within the bathroom. However in the same building within York Library, not only was the wheelchair that was offered for hire not charged, but nor was the hoist in the bathroom. This meant that the wheelchair users in the library had to charge these themselves before using them, which should not be their responsibility.



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Facebook:	Like us on Facebook
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York CVS

Healthwatch York is a project at York CVS. York CVS works with voluntary, community and social enterprise organisations in York. York CVS aims to help these groups do their best for their communities, and people who take part in their activities or use their services.

This report

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