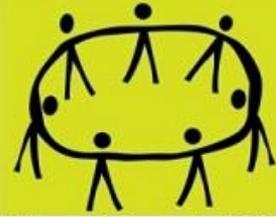


# PCAN



Registered Charity no: 1147436

Parents of Children with Additional Needs Making a Difference in Kirklees

## **Wheelchair Services Report on pre-consultation engagement work carried out by PCAN in conjunction with:**

**North Kirklees CCG**

**Greater Huddersfield CCG**

**Calderdale CCG**

**Voluntary Action Calderdale**

**Community Voices in Kirklees**

**Engagement Champions in Calderdale**

**Wheelchair users and their families, Schools, community groups and professionals across the district**

*"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

**Author: Carol Thomas**

**August 2018**

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## Introduction to PCAN

PCAN is an independent forum for parents and carers of children (aged 0 to 25) who have additional needs.

As a registered charity run by volunteer parent carers, we aim to support each other with information and friendship.

In addition, PCAN is the main point of contact for the Local Authority, NHS Trusts, service providers and other professional and voluntary agencies, who want to learn more about the views of parents and carers in Kirklees. We work tirelessly to ensure parents' voices are heard during the design, delivery and evolution of services for our children.

We are all parents of children and young people with additional needs and disabilities and are passionate about working with local providers to improve services. PCAN has a database of over 1000 families across Kirklees which is growing all the time and network with other local groups to widen our reach.

We receive funding from the Department for Education to act as an engagement partner with local service providers including statutory education, health and social care services. We also receive funding from Kirklees Council education and social care to enable us to work with them in co-production. This could be anything from co-producing the template of the Kirklees Education Health and Care Plans to significantly influencing the service specification for the Healthy Child Programme (which incorporates the CAMHS Service for Kirklees). PCAN has representatives in Kirklees on the SEND Strategy Group, Integrated Commissioning Group, Carers Strategy Group, Preparing for Adulthood Focus Group, Specialist Learning Group, Early Help Consultation Group and members are involved on an ongoing basis in the CAMHS Transformation Plan, new Early Support Strategy and other initiatives locally.

We collect anecdotal information from families on an ongoing basis via social events, meetings with local groups, and social media (closed Facebook group) which is fed into the work we do with the strategic groups above. In addition, we carry out specific pieces of research or are engaged by the Council to carry out engagement and consultation work to ensure that as many families as possible are reached and can share their views. Four of our Trustees are trained Community Voices and carry out engagement and consultation work on behalf of Greater Huddersfield CCG.

Our strength and expertise is around engaging with a diverse range of families with disabled children and young people.

## Background

In the Autumn of 2016, we regularly heard about problems that our members were having with the local wheelchair services provider, Opcare. Due to the growing number of negative comments we were receiving, and the lack of progress that our members were making in resolving their issues with Opcare, we contacted Healthwatch.

In February 2017 we worked with them to design a survey that could go out to our members and groups in our networks. During March and April 2017, PCAN supported Healthwatch to get these surveys filled in by inviting them to our groups and social events and getting the online link out through our networks. Healthwatch also carried out their own focus group meetings. They received 91 responses from parents and carers of children with additional needs and disabilities, and the findings were overwhelmingly negative. Their report dated May 2017 can be found in Appendix 1.

PCAN was invited to a meeting in July 2017 with other stakeholders at Opcare's premises in Elland to help create a stakeholder map to get the survey out to a wider group of people. A further survey was issued in September 2017 which was sent to all patients who have accessed wheelchair services during the previous 2 years as an effort to engage a wider group of people. The report and findings can be found in Appendix 2.

Following that we continued to contact our CCG colleagues for more information as we wished to feed back to people who had responded to the survey with some information about what was happening.

CCG's embarked on a service improvement plan with the current provider and Kirklees and Calderdale committed over £1m to clear backlogs by September 2018. (Calderdale CCG committed an extra £250,000 in non-recurrent funding to the service from its 2017/18 budget. In 2018/19 CCG's in Calderdale Greater Huddersfield and North Kirklees have all committed an additional £278,803 each to clear backlogs).

At the end of April 2018, PCAN was commissioned by the CCG to carry out pre-consultation engagement work to find out from local people what a good service would look like to them, what changes are needed to the current service and whether the CCG's are spending their money on the service effectively.

The purpose of these questions is to:

- 1 Inform the current service improvement plan
- 2 Inform the future service specification for the service (the current provider's contract runs out in September 2019)
- 3 To determine whether the clinical model of funding all levels (low to specialist) requires review.

## Approach

The first consideration to the approach to be used was the tight timescale of the project. The project timeline was to start with a stakeholder event on the 11<sup>th</sup> May 2018 and would finish with a further stakeholder event on 20<sup>th</sup> July 2018, both events to be organised and by Greater Huddersfield CCG and co-presented with PCAN. This gave a window of only 10 weeks to gather the required data.

During that 10 week period there was a week of school holiday during which parents would have very limited availability, school staff would be absent and too busy the week before the holiday and during the first week back to be engaged in a meaningful way. The week in question contained a Bank Holiday and is a very popular week for many people to take holidays. In addition, Ramadan ran from 15<sup>th</sup> May to the 14<sup>th</sup> June, followed by Eid ul-Fitr making it very difficult to engage with Muslim families in the area during that period.

It was decided that due to the short timescale, the optimum way to gather information would be via a survey and focus groups. PCAN would devise the survey, informed by the CCG presentation on the 11<sup>th</sup> May and the comments from stakeholders on the day. The survey would be available online and on paper and relevant people engaged in a variety of ways:

- At PCAN social events
- Via PCAN social media and networks
- Via CCG Community Voices and Engagement Champions
- Via local community and activity groups
- At parents' coffee mornings in schools
- In conjunction with Unique Ways, the Parent Carer Forum in Calderdale
- Direct contact care homes, support groups, community activity providers and so on based on the stakeholder list in July 2017. (This list was updated to include new, relevant additional contacts).
- Through social services departments, SEN staff, School Transport, Therapy Services, local Partnership Boards and other relevant Council bodies.

Whilst a number of issues were raised at the 11 May Event, PCAN felt that to include suggested "tick box" answers in the survey may suggest things to participants that they had not personally considered and could not be inclusive of all issues people might want to raise. (Respondents have a tendency not to answer an "any other comments" type question). So, a qualitative survey was designed to give participants opportunities to share their views based on their own experiences and ideas and be creative with their answers.

The survey contained three main questions plus an "any other comments" section:

What would a good service look like to you?

What changes do you think need to be made to the service you currently receive?

Do you think the CCG's could spend their money more effectively?

Examples were given underneath each question to prompt respondents. The survey can be found at Appendix 3.

The online survey was created on the 18<sup>th</sup> May 2018 (including an equality monitoring section based on previous CCG surveys) and a hard copy created. Codes were created to identify where responses had come from where possible.

The previous piece of engagement work identified that insufficient responses had come from young people, people from North Kirklees, people aged over 60 and Muslim communities. So, emphasis was put into reaching these groups during this piece of engagement work.

The stakeholder list was divided up between PCAN, CCG colleagues and Community Voices and Engagement Champions.

Meetings were held to brief Engagement Champions on 21<sup>st</sup> May and Community Voices on 23 May. PCAN distributed the online survey link across its networks from the 18<sup>th</sup> May and took the survey to regular events taking place on 22 May, 8<sup>th</sup> June, 19<sup>th</sup> June and 6<sup>th</sup> July. CCG colleagues contacted their list by email containing the online link. Various groups, activity providers and care homes and schools were visited by PCAN and CCG colleagues.

Resource material was produced by the CCG and shared with all partners carrying out the engagement work so that respondents could be as well informed as possible about the purpose of the survey and all partners tried to engage with with people in group settings so that this information could be discussed prior to participants completing the survey.

In total 467 responses were returned on the online survey broken down as follows per ID code/organisation name. 291 of these came via the Community Voices and Engagement Champions whose code starts with CWS or HWS.

Code	Organisation	No of surveys
HWS1	Mould Green	7
HWS2	Oasis	13
HWS4	Denby Dale	38
CWS1	Disability Partnership	40
CWS2	ACE	48
CWS3	Our Place	48
CWS4	Wheelchair Kurling	12
CWS5	CREW	22
CWS6	WES	30
CWS7	Unique Ways	3
CWS8	DART	10
CWS9	Disability Support	20
PCAN/PC00	Various PCAN networks	6
PC01/taleem	Taleem Centre via PCAN	2
PC05	Kirklees College via PCAN	5
PC07/Fairfields	Fairfields School via PCAN	7
PC09	Streetbikes via PCAN	5

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PC10	Down's Syndrome & Friends via PCAN	9
PC11	Muslim Families North Kirklees	13
PC19	Tolerance Group	1
	Forget me Not Trust	5
	Castlehill school	2
PCAN webpage		4
Milen Care	Milen Care	38
RCC		17
No code	Completed online	58

Equality Monitoring can be found at Appendix 12

In addition to the surveys, information was gathered via focus groups at the two events on 11<sup>th</sup> and 20<sup>th</sup> July and at Newsome High School Disability Sports Group. (Total 112 participants).

## Findings from Online Survey

### Question 1: What would a good service look like to you?

#### Key Themes



#### Repairs

Repairs, maintenance and spares were very significant issues for many respondents. It came up 257 times across the online surveys for this question. Respondents reported a lack of clarity about who is responsible for repairs and maintenance, issues about engineers coming out with the wrong parts, and how long it can take to get the right parts. Power chair users reported concerns about breakdowns and what would happen if they broke down whilst out and about, not at home.

Respondents highlighted how critical it is for the person who takes the repair call and the engineers to understand the implications for the customer of not having a working chair. People are waiting too long for their equipment to be repaired. In the meantime, they are unable to go to work, go out anywhere, take part in normal activities; children are unable to attend school, parents must take time off work to care and so on. In addition, broken chairs have a detrimental on the user's physical and mental health.

The cost of sending engineers out multiple times due to lack of parts to repair a single fault was highlighted by many. Many people felt that enhanced record keeping about chairs issued would enable a more effective stock of regular spare parts, improve efficiency, and would highlight where particular parts or models were frequently needing repair (perhaps suggesting that the equipment is not robust enough or nearing the end of its useable life).

Respondents suggested more specific appointment times for repairs, not waiting in all day, text reminders and updates. Data collected reflected and reinforced much of the feedback in previous engagement.

### Comments about a good service related to:

- Provision of a comprehensive and quick call out and repair service
- Call Centre for repairs
- Engineers need to be able to repair on site where possible, not removing chair
- Never leave someone without a chair, or with a broken chair
- Clarity over who is responsible for spares and repairs
- Replacing old chairs that need constant repair
- Users should be updated on repair status, not having to chase provider
- Understanding from repair service about the impact of not being able to use the chair
- A child with no chair or broken chair cannot attend school or access school transport
- Repairs carried to a high standard
- Provision of better quality equipment so fewer repairs are needed
- Provision of a 24/7 breakdown contact number (especially for power chairs)
- Ensure stock of regularly used parts
- Ensure engineers have correct parts prior to appointment
- Engineers have adequate training to do the job
- Same day service for complex users who can't manage without their chair.
- Accurate appointment timings (and keeping appointments)
- Urgent appointments for complex wheelchair users
- Repair clinics taking place in schools or residential settings where there are significant numbers of wheelchair users
- Fit for purpose replacement chairs if main one is away for repair.
- Repairs should be available for privately funded and charity chairs
- Advise people when engineers are going to call, eg. Text and not having to wait in all day

Repairs should be carried out to a high standard, and in a timely manner to prevent repeated call-outs.

quite  
il inf

Repairs are shocking, they refuse to see you if the seating base is specialised, this should not be the case.

rsfield  
775410

They need to come out more and do things on site instead of taking a chair away and it not coming back for ages

## Ongoing Maintenance and Safety Checks

Many respondents were concerned about the ongoing safety of the item they rely on so much for all their activities and suggested that regular safety checks should be carried out. Power chair users suggested that their chairs should be regularly maintained or serviced as you would with a car and accurate records kept. Others suggested that all chairs should be regularly maintained which could cut down on repairs and save money in the long run.

People who are willing and able should receive training on basic maintenance to help keep their equipment in good order.

### Comments regarding a good service related to:

- Clear information at point of issue about repairs and ongoing maintenance
- Planned, regular safety checks for all chairs supplied (including manual chairs)
- Maintenance system like regular servicing and MOT's for power chairs
- Proactive not reactive approach to repair service would save money
- Training of users and carers on basic maintenance they can do themselves

Maintain a service schedule for each wheelchair issued regardless of whether it is self-propelling, manual or motorised.

Equipment should be serviced annually at a minimum with an option to contact the service sooner for any interim issues.

Maintenance schedule like car MOT's. Could save a lot of money on repairs and give user peace of mind.

## Equipment

Respondents were very clear about what a good service should look like in relation to equipment and many of them had had very mixed experiences. A few people said they had received equipment quickly, the majority had not and raised issues about equipment fit, quality, delivery timescales, parts, ongoing maintenance and so on.

Lots of people commented on how important their wheelchair is to them (for instance people described their chair as "their legs", "their limb", "their independence") and discussed the implications for them of having an unsuitable chair or inappropriate postural support. Many respondents were dissatisfied with the fit of their chair, and that it caused them pain and discomfort. Comments revolved around quality and robustness of equipment, range/choice of equipment available, extras available, availability of rental or loan equipment, appropriate replacement or transit chairs, options to make a chair easier to use, prompt supply of equipment following assessment. Particularly those who had waited so long, the chair no longer fit them (particularly children). Some respondents felt that budget was more important than supplying a chair that met their needs. Plan ahead for equipment that will be needed in future.

## Comments related to:

- Provision of quality, robust equipment (not necessarily more expensive)
- Provision of the right chair, first time
- Unsuitable wheelchairs and/or postural support can cause physical injury and exacerbate existing health conditions – service should respond accordingly (hidden cost to the NHS)
- Unsuitable wheelchairs have a detrimental effect on social life, work, education, health and wellbeing not just physical access.
- Equipment supplied must meet all needs, not just clinical
- Selection of equipment should be needs led, not budget led
- Quick turnaround of equipment
- Suitability of equipment for transportation (eg. Type of car, straps for school transport etc)
- Availability of second hand equipment – however this must match the patient's needs, not be a cheap fix
- Wider range of equipment available
- Being able to try out equipment or at least see it before issue (showroom)
- Availability of more lightweight wheelchairs where family members, carers and staff are pushing them, lifting them into vehicles.
- People should not have to fight to get the right equipment
- The service should understand that people have no independence without their wheelchair
- Provision of equipment that is suitable for people's lifestyle needs

Chair needs to be fit for purpose. Not everyone sticks to pavements – some people go through fields etc

My current chair is too big which affects my posture. I am told to put up with it – they can't do anything. This has made me housebound for 2 years and caused further health issues

One size doesn't fit all, more options needed. It's a bit like shopping for clothes, you need variety of choice, options and sizes. If it doesn't feel right you will struggle to get through an hour let alone a full day!

## Referrals

The majority of comments relating to referral suggested that a good service would have a clear referral process that is easy to find out about and a confirmation from the service that their referral had been received with information about what happens next. A significant number of respondents reported difficulty in finding out about the wheelchair service and

how they could get a referral. Respondents commented that the Opcare website lacked relevant information. Many people commented on the timescale between referral and assessment which for some was weeks or months. Some respondents never found out about the service and bought their own equipment. Other professionals did not tell them about the wheelchair service.

#### Comments related to:

- Clear and comprehensive information about how to get a referral (including clarity on the service website)
- Confirmation from service that a referral has been received and what will happen next (shouldn't have to be chased up by patient or family)
- Should be able to self-refer
- Other agencies should know about the service and how to refer
- Information provided on how to refer back into the service if condition changes/worsens
- Easy journey from referral to getting the best outcome

Everyone should know how to refer. Publicise referral routes widely, in hospitals, GP's, libraries, Gateway to Care etc

No-one told me how to get a referral for assessment, so I bought my own and now can't get it repaired.

Information leaflet available in easy read to describe the process of referral and how the service operates

#### Assessment and Review

Very few respondents reported receiving a timely assessment and many felt that the assessment they did receive was not sufficiently person centred. Users and carers felt that their views were not always listened to regarding their lifestyle needs and that the approach was budget or service led. Some people did have a good experience of the assessment but felt that there was no information about what would happen next. There were issues about the timing and location of assessment appointments, notice of appointments of changes to them and the communication after the assessment. Timescale and pathway were issues – shorter timescales between referral and assessment and assessment to receipt of equipment and a clear pathway about what happens at each stage.

Respondents with complex needs and parent carers highlighted the need for regular planned review and re-assessment to take account of changing needs, degenerative conditions and children's growth. They shouldn't have to be chasing and waiting for months.

There should be a follow up after receipt of equipment to ensure it is meeting needs.

Data collected reflected and reinforced much of the feedback in previous engagement.

## Comments regarding a good service related to:

- Assessment needs to be a holistic, person centred process based on user needs around lifestyle, home, any vehicles used, work and leisure as well as clinical need to ensure that the resulting equipment meets the customer's needs.
- Assessor needs to listen to the user and/or carer to understand fully what their needs are
- Assessments to take place in locations other than Elland. Easier for people to access in localities
- Regular reviews and re-assessments, particularly for growing children and people with degenerative health conditions – should be built into system and happen automatically.
- Assess discomfort or health problems caused by chairs urgently to minimise additional health problems or injury
- Discuss non-standard options during assessment which could be helpful to the user or carer
- Explain fully any cost implications for the user at point of assessment, eg. Extras which can be purchased
- Urgent assessment appointments to be available for emergencies and people with life limiting conditions
- Allow more time for assessments for complex needs so it can be a fully holistic process
- Realistic information about timeframe for delivery of equipment following assessment
- Prompt ordering of right equipment following assessment

A good service would be listening to family and carers about the person's needs if they are unable to talk.

A good service would meet the needs of the individual (person centred) as opposed to budget centred that meets the needs of the organisation.

Regular assessments and reviews for complex and high needs

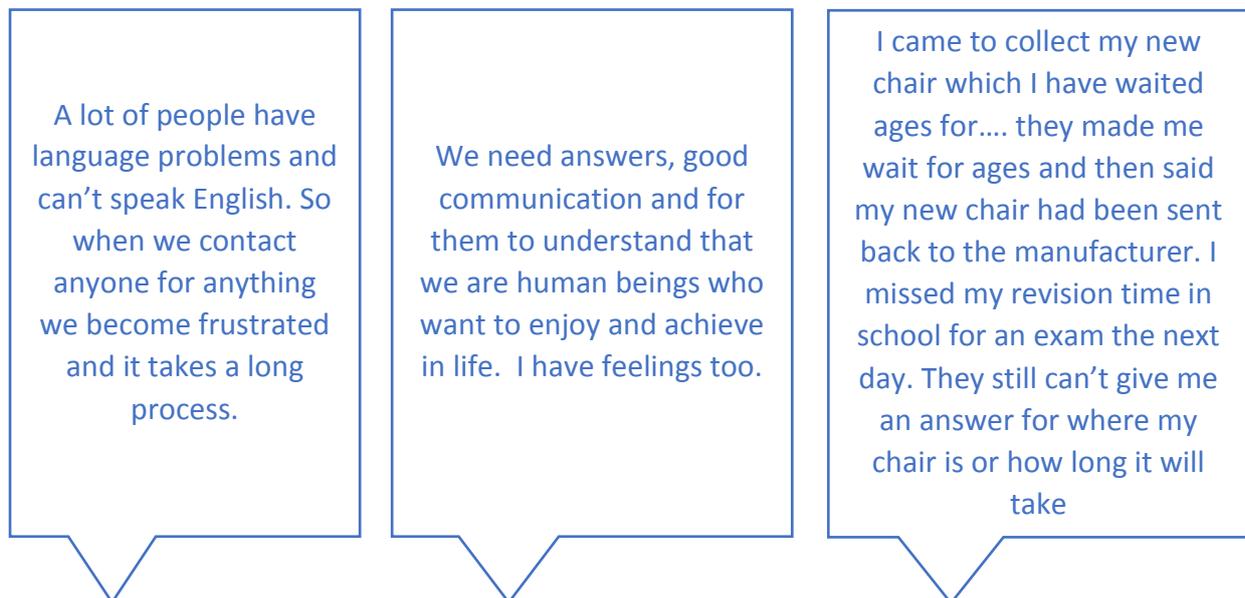
## Communication

Most respondents felt that effective communication is an essential part of a good service. Not just between provider and patient, but internal communication within the service, and communication with other agencies, such as adaptations team, schools, therapists and so on. Most respondents expressed dissatisfaction with their experiences of communication from the current provider. Respondents felt that a good service would include timely and

honest communication, calling people back, and use of technology such as text reminders of appointments, use of email and other digital technology.

#### Comments regarding a good service related to:

- Effective internal communication between individuals and departments
- Effective and timely communication between service and customers
- Keeping people informed of progress at all stages
- Effective communication skills during assessment process (asking questions, listening and taking account of responses)
- Effective internal communication system, eg call log that others can access and ensuring that information is passed on to the right person. Clients should not have to make repeated calls.
- Accurate communication over appointments and changes to them
- Accessible communication system for deaf people
- Staff who speak community languages or provision of interpreters for appointments
- Improved communication between school, transport and wheelchair services
- Enhanced communication between Opcare staff and technicians regarding repairs and parts
- Acknowledgement of referral to service
- Open and honest communication – transparent and accessible
- Use of technology to improve communication
- Understanding the implications of poor communication.



A lot of people have language problems and can't speak English. So when we contact anyone for anything we become frustrated and it takes a long process.

We need answers, good communication and for them to understand that we are human beings who want to enjoy and achieve in life. I have feelings too.

I came to collect my new chair which I have waited ages for.... they made me wait for ages and then said my new chair had been sent back to the manufacturer. I missed my revision time in school for an exam the next day. They still can't give me an answer for where my chair is or how long it will take

#### Pathways and Timescales and waiting times

Survey responses showed that having a clear pathway with realistic timescales is an essential part of a good service. It is equally important for someone new to the service and existing customers who need to come back into the service for equipment review and/or replacement. As indicated above, many respondents had to wait a long time at various if not all levels of the service and advance information with realistic and achievable timescales would help to assure people that they have not been forgotten and manage expectations.

There was acknowledgement that pathways and timescales would be different for people with different levels of need as the process would be different and take longer for complex needs. However, maximum times should be given and adhered to. Consistency of staff from start to finish where possible. Survey comments reflect and reinforce feedback given about waiting times in previous engagement.

#### Comments related to:

- A good service would understand the implications of extended waiting times for wheelchair users
- A clear pathway to be provided of what happens from referral to delivery of equipment including training opportunities and information about aftercare
- Need to know how to go back to the service to get a replacement chair (clear pathway needed)
- Information should be provided on the website
- Clear information about timescales to be given (shown on pathway)
- Clear pathways for each level of need
- Professionals as well as patients should have pathway information
- Visible pathway plan (flowchart) showing who does what, where and when with timescales
- Pathway for repair reporting, who to call, what will happen and when
- Clear contact information if you have queries along the pathway
- Include how to get back onto pathway for review or replacement equipment
- Improved timescales (standard 8 weeks to max 18 weeks) for provision of equipment
- Improve timescale for repairs
- Equipment to be ordered in a timely way after assessment
- Clear timescale of what will happen and when at all stages
- Individual timescale from assessment to delivery of equipment
- Reduce timescales for all elements of the service
- Lack of funding should not be a reason for not supplying much needed equipment

A visible pathway plan that we can all see online that works and is clear. The plan tells us exactly who does what, when, where and contact numbers.

Maximum timescales for proceedings mapped out in a clear pathway

Timescales need shortening. Getting assess takes too long and often old people die before receiving equipment they desperately needed.

#### Information

As indicated by some of the above comments, there seems to be a lack of information about the service, who it supports, what it does, how to be referred, not just from the perspective

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of potential users of the service but also from that of other professionals that they deal with. Information was a broad topic area and included feedback about everyone receiving the right information (staff and service users) at the right time, information about the process (as discussed in pathways above), information about all options including financial, information about external organisations and agencies, and information about aftercare and support. A good service would include:

- Comprehensive, easy to read information about wheelchair services – for professionals and service users
- Clarity about the service offer – what it is, what it does, who it serves etc
- Clear and accurate information given to people when they need it
- Information to be provided in an accessible way for different users
- Being given information about what to do if not happy with the service
- Collection of information needs to be accurate
- Information about where power chairs should be stored
- Accurate information about whether power chair batteries can be taken on a plane
- Giving information in a timely way
- Information about range of wheelchairs available
- Information about what type of wheelchair to buy if issued with a voucher
- Ensuring engineers receive correct information about repairs/parts
- Ensure that information is passed on to the right person
- Information to be given to user on receipt of equipment regarding after care, maintenance, breakdown number, insurance, contractual obligations – should be clear, simple and jargon free
- Information on pathway and timescales
- Information about funding options, including vouchers, personal budgets and self-funding
- Information about helpful local groups, other agencies for support
- Information to be given for all options, whether through NHS or external supplier
- Access to online information, eg. Order tracking, repair tracking
- Information about how to use equipment and training
- Informative comprehensive website

Families should be given the right information about what to do if receiving a poor service.

Information needs to be given about insurance. I was not aware I had to insure my chair.

There needs to be a website that shows the policy, contact details and information for wheelchair users without jargon.

## Training

Training was regarded by many users as an essential part of a good service. Comments about training were mainly around training for users, carers and support workers but also referred at times to staff training, especially around disability awareness and what it's like to

be a wheelchair user. Lack of empathy by staff was cited as an issue in this piece of engagement work and in previous findings. Training, particularly delivered by wheelchair users, would support people's understanding of the issues.

Respondents felt that the following would be integral to a good service:

- Comprehensive training on using the equipment provided for users and where applicable, carers, support and school staff (to preserve carer health and safety and maintain safety and comfort of user) at point of delivery
- Training on how to navigate different terrains, go up and down kerbs, manage hills.
- Training on basic maintenance that can be carried out at home to care for the equipment
- Training to be provided at point of receipt of equipment, not afterwards.
- Training on how to do basic safety checks on things like brakes.
- Training on what do if you fall out of your chair
- Training on using public transport
- Training for use indoor and outdoor including the user's home environment
- Staff training about what it's like to be a wheelchair user (including spending time in a wheelchair to understand user's perspective)
- Training on folding wheelchairs to go into cars and how to lift them safely
- Training to be considered case by case, not generic
- Training essential even for basic chairs, how to get into car, go up kerbs safely etc

Training grounds and driving lessons. These lessons should have ramps, hills, different surfaces, obstacle course, moving round bends, furniture and doors.

Immediate training to be given at home environment, indoor and outdoor on delivery day.

Staff need to be re-assessed on their training every year to make sure they are up to date on everything

## Advice and support

There were numerous comments about advice and support being part of a good service, many of which were not specific about the type of advice and support required. Several respondents talked about advice about equipment they should purchase if issued with a voucher or if they wished to self-fund and would like that to be part of the service. Some comments on advice alluded to training - advice on using wheelchair correctly etc. Some respondents talked about peer support from other users, and aftercare or ongoing support from the service regarding how they were getting one with the chair, repairs and maintenance. Others talked about advice if they didn't qualify for a chair from the service but had to buy their own.

Comments included:

- Provision of advice and support
- Advice on what type of wheelchair to purchase
- Advice and support from local support groups and other wheelchair users
- Support after receipt of wheelchair including training, how to access repair service etc
- Peer support group

If we have to buy our own chair, we still need advice and guidance on which chairs are suitable for our use.

It would be nice if you could get to speak to someone when you need advice and support

Support should be as and when it is needed with support or advice, initially by telephone or appointment if needed

## User involvement

Some respondents felt that involvement of service users in various ways would be part of a good service. This included, befriending, service evaluation, having an advisory group and employing wheelchair users as volunteers and in paid roles in the organisation. More comments were made about user involvement in questions 2 and 3. The following would be integral to a good service:

- Service user involvement at all levels
- Local user groups to be more involved
- Friendly users to recommend equipment, offer help, support and friendship
- A user group to monitor feedback about the service
- Users to create a set of guiding principles for the service
- Service users to be employed in workforce admin
- Train volunteer users for various roles, support, befriending, training
- Has advisory group made up of service users and carers
- User led CIC to provide loan store
- Learn from users' experiences

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- Obtain regular feedback from users of the service
- Listen to users' suggestions for service improvement
- Involve users in product testing

Employ service users and have an advisory group

Any new changes need to be thought through properly and must involve service users more than surveys and reports.

A buddy system to help with training

## Appointment Times and Location

Many people felt that the appointment system is rigid, linked mainly to one location and they wait too long to be seen. A good service would offer a more flexible system with straightforward access and a variety of clinic locations. A variety of times should be on offer, not just 9-5 Monday to Friday. Appointments could be booked online or over the phone a bank of appointments should be available for urgent re-assessments or emergencies.

- Flexibility about appointment times
- Recognising that carers may have to take time off work to support someone to attend an appointment
- Out of hours appointments available, including weekends (working around work and school hours)
- Regular clinics in other areas – Elland difficult to get to for many
- Regular planned clinics to be held in special schools, day centres, hospices and residential homes
- Adequate notice of appointment times (unless offered cancellation)
- Appointments could be offered differently, eg. Giving notice of what month appointment will take place and asking user/carers to phone and arrange convenient time/date
- Ability to book online appointments if needed
- Joint appointment with therapist or rep and trainer at point of delivery, so chair can be adjusted, and user trained to operate it.
- Fixed time appointments, not waiting all day for a visit
- Appointment reminders to be sent out (text)
- Quicker access to appointments – should be able to get an appointment in 2 weeks
- Fast track appointments for rapidly progressive conditions, end of life conditions, high risk, or current seating causing pain or skin damage

High priority appointments for wheelchair users who are permanently in the wheelchair

Appointments should be made over the phone so that we can arrange a time suitable and convenient for all.

Services need to be in local area and easy to access

## Organisation and Ethos

Respondents to this survey felt that a good service would be friendly and accessible with well-trained staff who understand the difficulties faced by wheelchairs users, have appreciation of the complexity of their condition and the fact that it can change over time, can respond in a timely way and show empathy. Compassionate and responsive customer should be a priority. Clear timescales and pathways, easily accessible information. Good

record keeping, simple to use systems, embrace digital technology for those who can access it.

A good service should:

- Be Understanding of the needs of service users and carers
- Be aware of the implications of waiting for appointments, equipment or repairs and respond accordingly
- Understand that children's needs change all the time
- Recognise that the same condition will affect individuals in very different ways and not take a "one size fits all" approach
- Take a holistic person-centred approach at every level in the organisation
- To recognise that not every disabled person has a learning disability
- To recognise that most disabled people can speak for themselves (not through their carer)
- Enable patients to feel that the organisation cares about them and their welfare
- Strive to offer excellent customer care
- Understand that people's health conditions can change, sometimes very quickly
- Well trained staff with appropriate skills who care about the clients (particularly admin staff)
- Well organised with clear pathways
- Respond to customer complaints appropriately
- Recognise where problems are emerging and deal with them in a timely way
- Be accountable for the service provided
- Have slick systems and less bureaucracy
- Involve users throughout the organisation

Need good customer care - compassion, greater understanding

Clinicians and technicians should be competent and trained to interact with different people with difficult needs and problems

Staff need to be more sympathetic when we are trying to address our concerns. They need to remember that facial expression and attitude says a lot.

## Sufficient Funding

Throughout the responses there have been direct or indirect comments about funding. This may have been about budget led approaches, inability of the service to order equipment due to lack of funding or approaches to saving money costing the NHS more in the long run in treating injuries, more appointments and mental health issues. There were comments about money being wasted, wrong equipment being ordered, equipment being ordered too late so was no longer fit for purpose, wrong parts being ordered and repair teams going out too often without the parts needed or the knowledge to repair. People said the system was

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disorganised which also cost them money and stress; taking time off work unnecessarily, expensive taxis, struggling on public transport and constantly having to contact and chase the organisation. Very few respondents reported a good service from start to finish.

Here are some quotations from respondents:

A good service should focus on my daughter's needs without reference to cost

Financial sign up for equipment needs to be speedy and efficient, should not have to wait for 4 months plus

Funding – required budgets to be available to support this service effectively

My child has a life-limiting condition. The last thing I want is to fight for services...I had to get my MP involved only to be told that there is no money

You can throw money at the service but if they haven't got the right staff it won't work

A good service is one that is all about the service user, not about money

Too many people involved in the process. Need to make it simpler. This will save time, money and frustration

Money wasted ordering the wrong parts is a regular occurrence. This covers wasted appointments, parts, labour etc.

There is no point in not placing enough money into someone's health as this only leads to more detrimental problems costing the NHS more

## **Question 2: What changes do you think need to be made to the service you currently receive?**

All the comments here need to be reviewed alongside the corresponding themes in the question above (what would a good service look like?).

### **Repairs and ongoing maintenance:**

Most respondents suggested that waiting times for repairs need to be improved. There is some overlap here with Question One where many respondents suggested 24/7 call out, information about who to contact, clear timescale for repair or parts, regular safety checks and regular servicing for power chairs. They also referred to having a sense of urgency and having some understanding of how difficult it is to manage with a broken chair. Additional comments on changes to the service included:

- True appreciation of how long waiting times can impact on a person's health and wellbeing, increasing their level of disability
- Range of small local providers who can deal with repairs eg. Experience Community
- Offer repair service to users who have chairs purchased through vouchers (paid for if necessary)
- More work with local user groups to help resolve this issue
- Drop in repair clinic or mobile van
- Set up approved suppliers with service level agreement for repairs and spares
- One central point of contact for repairs
- Repairs service needs complete overhaul – appoint new manager with expertise on stock management to reduce time and money on wasted calls
- Same day response for children and complex users
- Analyse spares regularly used and chair models that are out there to help purchase relevant stock of spare parts.
- Rationalise range to focus on reliable equipment.

### **Equipment**

As above, most respondents felt that the equipment provided should be more robust and meet their needs. Equipment should be provided within reasonable timescales and that they should be kept informed at all stages. Equipment should be fit for purpose and right first time. Respondents felt that better quality equipment would stand the test of time and need fewer repairs (more cost effective). More people talked about having more choice, and chance to look at equipment or try it out. Many people referred to their response in question one.

Additional feedback included:

- Follow up to ensure that the equipment is meeting the user's needs
- Provision of equipment that meets people's needs (not just stock equipment)
- Tracking system so users can track equipment orders

- Showroom where equipment could be seen or tried out.
- Have experienced staff who understand that people's lives depend on this equipment

## **Referral**

There were limited responses specifically about referrals. Most respondents referred to what they had said in question one, with reinforcement of the fact that information about referrals is lacking.

## **Assessment**

Comments about assessment were very similar to those in the previous question, more emphasis being put on having comprehensive information about all aspects, as well as the assessment being a truly holistic process.

Additional feedback included:

- More holistic assessment with full discussion of options available
- Comprehensive information given at point of assessment
- Could GP's do low needs assessments to take pressure off the service
- Referral or signposting to other agencies as needed, eg. Adaptations team, mental health services/support (for stressed people who have waited a long time)
- Signposting to local support groups
- Involvement in some way of expert wheelchair users

## **Communication**

Comments here reflected what was said in question one or respondents referred to their previous answers.

## **Pathways and Timescales and waiting times**

Comments here reflected what was said in question one or respondents referred to their previous answers. There were a significant number of comments about reduced waiting times from referral to receipt of equipment.

## **Information**

Comments here reflected what was said in question one or respondents referred to their previous answers.

Additional feedback:

- More (clear) information about personal budgets and vouchers

## **Training**

Comments here reflected what was said in question one or respondents referred to their previous answers. There were additional comments about training for carers and their health and safety being paramount as well as more comments about staff training and users being involved in training.

## **Advice and Support**

Comments here reflected what was said in question one or respondents referred to their previous answers. As with the previous question, several respondents referred to better advice and support but with no specific information as to what type of advice or support. There were significantly more comments about support from service users and expert users as well as being signposted to local groups for support.

## **User involvement**

There was a strong feeling that wheelchair users should have a part in the organisation on a paid, not just voluntary basis. They are the only people who understand what it's like to be their shoes if a chair breaks down or have to wait an inordinate length of time for equipment. Wheelchair users in this capacity should be representative of all communities.

Their expertise could be channelled in various ways: helping to support new users, supporting training design and delivery, using their valuable lived experience about different models of chair and the advantages, disadvantages of each, working alongside a clinical provider as a joint enterprise, and contributing to the new service specification, involvement in the tender process and ongoing monitoring and evaluation.

Comments included:

- Involvement of service users to help others – not just from one group, but selected based on their experience
- The idea of wheelchair users as a provider
- A mix of professionals and users would provide good advice and information
- Involve wheelchair users in the service specification and ongoing
- Like the idea of expert wheelchair users being around at assessment, not just therapists
- Knowledgeable wheelchair users to be involved in training, especially ones who speak Asian languages
- Service should be a joint organisation with a user or disability group and a clinical partner
- Expert wheelchair users advising on different wheelchair models
- Wheelchair users to form an advisory panel to meet with CCG say once every 3 months
- Buddying new wheelchair users especially if they have similar models of chair

- Paid users with the rights skills employed by the organisation (with reasonable adjustments for access etc)
- Involvement of wheelchair users to co-design, deliver and evaluate the service as part of the commissioning team, not provider
- Every new user should have the choice to have a “buddy” – experienced wheelchair user
- Refer people to local wheelchair user groups for support and information
- Involvement of wheelchair users in the organisation must include people from all communities.
- User involvement could be used to identify what is good practice and provide staff training and mentoring
- Continued effective engagement with service users and carers and take action (You said, we did)
- Evaluation to be gathered from all users to ensure good practice and make improvements

## **Appointment times and location**

As with the previous question, respondents felt that there should be more flexibility about appointment times on offer and a range of locations for people across the area. A large number of respondents referred to a one-stop shop with assessment, information, showroom, call centre, after hours service, modifications, supply and returns, fitting, stock of basic chairs available in a central location. There were a number of suggestions about a central location in Halifax or Dewsbury. As previously there were a lot of comments about improving the timeframe for appointments.

## **Organisation and Ethos**

There was considerable support for the idea of a one-stop shop, one central place for organisation with other locations for assessment to meet the needs of the population. As previously mentioned there was support for the idea of a joint organisation with service users and carers. In terms of ethos, the comments reflected what was said in question one about attitudes, customer care, communication and understanding.

There were additional comments about improved organisation:

- Use of IT systems at various levels
- Improved record keeping so people did not have to keep repeating their story
- Consistent staff or key workers where possible
- More forward planning – people not having to wait for replacement of obsolete chairs, and being proactive where they know people having changing needs

## **Accountability:**

Whilst there were comments about saving money and working in a more organised efficient way as in question one, there were additional comments relating to the organisation being more accountable:

Feedback related to:

- A clear complaints procedure and accountability
- Accountability for service errors
- More emphasis on transparency
- Listen to what service users are saying and use feedback for service improvement

### **Question 3: Do you think CCG's could spend their money more effectively?**

#### **CCG performance, monitoring and accountability**

Whilst there was acknowledgement that the CCG's have a very difficult job to share out resources in a climate of austerity and generally do a good job, there have been long term issues over wheelchair services in Calderdale and Kirklees which need to be addressed. Respondents felt that the obsession with the budget is counter-productive to effective spending.

- CCG should have robust monitoring processes in place (not waiting for a crisis before reacting) and accountable
- Money is being wasted trying to put things right
- CCG should look at each level of spend and determine how much it (truthfully) costs to run an effective service that meets people's needs
- CCG need to be aware of the hidden costs of not providing appropriate equipment
- CCG need to performance manage the service far better than they have. The same problems come up at every piece of engagement with users.
- Cutting budgets all the time is not an option, eventually the system fails
- The CCG's should be investing in the service to prevent other costly health interventions
- The CCG should be more involved with service users ongoing, evaluating the service
- The CCG needs to be realistic about how much money this service needs. Underfunding has caused all these problems.
- Who audits how CCG's spend their money? Users should be involved in this
- The CCG should allow people to self-fund when they can or want to. Charge deposits or low fees for rental items instead of free – most people can contribute something.
- The service should to be needs led, not budget led. CCG need to understand this
- Introduce clear system for personal budgets

#### **Funding (at each level)**

There was a variation in how people viewed this, and a lack of understanding or clarity on what constituted low and medium need – are people being classified correctly?

Respondents cited incidences of people who started off as low need then moved up the levels, or who had a degenerative condition but were still assessed as low need, even though this falls into the medium need category. Some people felt very strongly that the CCG should fund all levels regardless of need – like all health services, but others felt that people should part fund, be means tested or access loan/refurbished equipment possibly with a deposit. There were high/specialist needs users who would have liked to contribute because they could afford it but weren't able to. Some people felt that CCG funding is inadequate for the service as there have always been backlogs and delays, others felt that the funding should be applied proportionately to the levels of need (more money allocated

to high and specialist need – this seems to be where the waiting lists and delays are and the service cites lack of funding as a reason for delaying or not providing equipment). A disproportionate amount of money seems to be spent on low need – is that because it is easy and quick to deal with? Many people commented that they did not have sufficient knowledge or information to be able to comment in this area.

User comments are as follows:

- 26 respondents specifically stated that the CCG should fund all levels of need.
- 10 respondents said specifically that the CCG should not fund the low level.
- 11 respondents suggested introducing means testing (like optician or dentist) for eligibility for free equipment
- 16 respondents stated that the spending should be proportionate to the levels of need of people in the service. (how the money is being spend should be public information)
- Some people (4) talked about the opportunity to top up fund, although this was in relation to having the choice to buy a higher specification and topping up the different themselves
- Several people suggested having a loan store of new or refurbished equipment to be available for low need users. This could be provided free (on loan), rented or purchased.
- Don't know enough about this to be able to comment
- Don't understand how funding works
- Continue to use vouchers for low need
- Have the opportunity to contribute financially because you can or want to at high or specialist need level.
- Have a collection service to get old unused equipment back so it can be refurbished and re-used.
- There were comments about the use of personal budgets which will be covered in the next section
- A review is needed of spending in each section, so that a realistic budget can be set for each level

## **Personal Budgets**

Many respondents felt that they did not know enough (or anything) about personal budgets so couldn't comment on how useful they would be. Some respondents said "yes" to personal budgets without any comments on how they could help. Lot of people were positive to the idea of personal budgets provided there was a clear and transparent process, it was fully explained to the user and would not be a burden on them to administrate. It was acknowledged that some people would not be able to understand or manage a personal budget. Some people were alarmed and hoped that money going into personal budgets was not a "hidden cut", or that it would reduce other services on offer. There was a lack of clarity about whether using a personal budget for wheelchairs would affect people's other personal budgets, eg. For social care or education. The offer needs to be very clear and

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distinct from personal budgets people may access (everyone uses the same terminology – very confusing for users).

Comments included:

- Yes to personal budgets
- Need more information on personal budgets
- Not sure what personal budgets are
- Personal budgets would make the system more personalised and increase choice (users could make the best decision for themselves)
- Personal budgets could prevent mismatches of client with unsuitable equipment
- Personal budgets may not work if people are left without vital equipment because the cost goes over their allocated budget.
- For personal budgets to work there needs to be lots of discussion over how it would work and a focus group with users and carers to co-design what it would look like
- Personal budgets should not be a way of cutting back resources
- Using a personal budget should be an option, not mandatory
- Personal budgets could be complicated and difficult to manage for some people
- Allocation of personal budget should be needs not budget based (should be sufficient to cover needs)

### **Cost saving and efficiency**

There were comments in all questions of the survey about how the current service could save money and operate more effectively. Most respondents suggested that purchasing better quality, more robust equipment would have an overall economic benefit. It would last longer, need fewer repairs and not necessarily cost much more. Regular maintenance could prevent costly repairs and engineer call outs. Invest in equipment that fully meets people's needs so that it is not constantly being changed and prevent costly health interventions. Holistic assessment and provision of the right equipment first time. Introduce means testing for low levels of need, operate a loan store of refurbished equipment (could be run by service users), allow people to contribute financially if they want.

Comments related to:

- Have a store of reconditioned or second-hand equipment
- Purchase more robust, better quality wheelchairs
- Meet people's needs first time round (duplication of effort costs money)
- Plan ahead so that budget can be tailored accordingly
- More or proportionate spending to go on high and complex needs to save further damage to health
- Set a realistic budget in the first place and make saving along the way
- Service should be non-profit or profits are ploughed back into the service
- "Saving" money by not meeting needs is a false economy
- Focus on saving money operationally so that money can be spend on customer

- Reduce the waiting list – delays cost people’s health
- Specialist locations would help reduce cost
- Running a more efficient service would reduce costs – having clear pathways and timescales so people are not always ringing up with problems.
- Train users and carers on basic maintenance

Comments in Questions 1 and 2 also link to money saving. There are many comments about staff training, clear pathways and timescales, effective repairs and spares service, timely provision of equipment, provision of the right equipment first time and so on. These contribute to service improvement but also to the efficiency and effectiveness of the service making it more cost effective. Crisis management is expensive.

### User involvement

- User groups need to see that the money for the service is being spent proportionately and according to need
- Co-produce personal budget offer with service user focus group
- Include service users in the tendering process
- Set up a user group for personal budgets so experiences can be shared and support evaluation of effectiveness.
- Get users involved to design more effective services
- Users need to be involved in designing the service specification
- Voluntary groups to train existing and new staff

### Question 4: Is there anything else you would like to add?

The topics from comments in this section mainly reflected what was discussed in questions 1, 2 and 3 so have already been summarised. A number of the comments were personal and related to experiences, described how they saw the quality of the service and expressed concern about getting it right this time. There were several comments about being seen as a number rather than a person. Gratitude was expressed by those who had received a good service and several respondents wanted to thank Opcare staff and associated professionals who work tirelessly and must be under a lot of pressure whether their outcome was good or otherwise. There were additional comments about profit making organisations and that the service should be run as a non-profit with surplus re-invested in healthcare.

Several people asked “will this survey make a difference?” The following quote sums up these comments:

It’s good that these surveys happen.  
And that improvements are being attempted but don’t forget that the true reflection of the quality of a service is the quality of the end user’s life, not the budget on paper.

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## Findings from Events and Focus Groups

The event organised by the CCG on the 11<sup>th</sup> May was to set the scene for the engagement work and also to explore the findings from previous pieces of engagement work. In the morning, participants were asked the following questions:

- 1) Is there anything missing
- 2) Is there anything else you want to tell us?

In the afternoon, the workshops followed on with the following questions:

1. What does good look like?
2. What else do we need to consider?
3. Can we use the money we have differently?

The majority of the comments reflect what has already been collated from the online surveys. There was some individual feedback which can be found in Appendix 8. Participants found it hard to understand or work with the information given about how the different levels were funded so many did not comment. Two out of the seven tables carried out clearly documented discussion about the 4 levels of need but most of the discussion was centred around the process, assessment and support. In each discussion there were suggestions about low need which could allude to funding: loan or hired equipment for low need was suggested by one, and offering the voucher scheme only by the other.

The stakeholder event which took place on the 20<sup>th</sup> July was to provide an update on the engagement progress, share emerging key themes and identify if there is anything missing.

The questions asked were:

Is there anything missing?

The majority of the comments reflect what has already been collated from the online surveys. There was some individual feedback which can be found in Appendix 10

The focus groups which took place at Newsome High School and Kirkburton hub mirrored the findings collected in the online survey. Individual comments can be found in Appendix 9.

## **Comparison to findings from previous engagement and reports**

There have been a numerous studies, reviews and pieces of research around wheelchair services carried out nationally over the past 12 years. These have come from government, statutory and voluntary sectors.

### **Moving Forward: Review of NHS wheelchair and seating services in Scotland. NHS Scotland 2006<sup>1</sup>**

Key Findings:

- The remit of the NHS Wheelchair and Seating Service should address the lifestyle requirements of users and carers ensuring maximum possible social inclusion.
- Service delivery should be based on holistic requirements and not coloured by available funding for equipment.
- The service should measure performance and demonstrate accountability.
- The service should be adequately funded to meet its core values - additional resources should be provided to fill large gaps that exist in current service provision.
- A multi-agency approach to deliver a seamless service, from the user and carer perspective, should be established at national level, delivered locally.

### **Out and About: Wheelchairs as part of a whole-systems approach to independence. Care Services Improvement Partnership 2006<sup>2</sup>**

Recommendations:

Whole-systems working and joint commissioning

Responsive, person-centred services

Access to assessment and information

Co-ordinated assessment and provision

### **Local Innovations in Wheelchair and seating services 2010, Department of Health Commissioning Team<sup>3</sup>**

Emerging Themes

- Focus on the needs of the user – wheelchair services should employ a holistic approach to assessment that considers the social, environmental and lifestyle needs of the individual alongside their clinical requirements
- Achieve timely access – providers should work with service users to identify and eliminate unnecessary delays in the assessment for and delivery of wheelchairs
- Ensure equity of provision – institute eligibility criteria that are transparent and evidence-based Improve outcomes for service users – providers should have clear and responsive processes for listening to and acting upon user feedback.

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Commissioners should use robust metrics to measure the quality of service provision from both a commissioner and service user perspective, including waiting times and product suitability

- Adopt a preventative approach to service provision – services should look forward to the medium and longer term clinical and social needs of the user when providing a wheelchair
- Shift the balance of resources from service management to wheelchair provision – commissioners, providers and service users should work closely to identify areas where productivity can be improved. Improvements should be quantified and re-invested into wheelchair and seating provision
- Encourages innovation – commissioners should encourage and empower providers to seek product innovation and procurement opportunities

### **Get Moving – the case for effective Wheelchair Services: Muscular Dystrophy Campaign 2013<sup>4</sup>**

(updated from original report in 2010)

Calls to Action: The Muscular Dystrophy Campaign is calling for the following actions to take place:

1. Clinical Commissioning Groups need to ensure assessments are based on a full understanding to the needs of the individual, taking into account elements such as age, the rate of progression of the muscle wasting condition, severity of the condition and lifestyle of the individual
2. The Department of Health should establish a national target for waiting times for wheelchairs at a maximum of 18 weeks from initial referral to delivery of the chair to minimise the impact of deterioration of an individual's condition during the period following assessment.
3. Clinical Commissioning Groups need to ensure better access to information and advice and improve their communication of how to access wheelchair services.
4. The Department of Health should increase the budget for access to powered wheelchairs within each Clinical Commissioning Group, as well as promoting better understanding of the benefits a powered wheelchair can bring to people with muscle-wasting conditions, which can in turn lead to cost savings by helping to prevent unplanned emergency admissions to hospital.
5. Clinical Commissioning Groups should pay for the cost of maintaining all wheelchairs, including those that have been modified or privately funded and maintenance of these wheelchairs needs be carried out quickly and efficiently. The current system requires clarification regarding eligibility for NHS-funded for people who purchase chairs privately.

6. NHS England and the Clinical Reference Group (CRG) for Complex Disability Equipment should ensure the effective implementation of the service specification of Complex Disability Equipment: Specialised Wheelchair and Seating Services.

**Right Chair, Right Time, Right Now, NHS 2014<sup>5</sup> - Report written following two wheelchair summits which took place in 2014**

Concluded that working together with stakeholders to improve services, we can expect to:

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

The themes above are captured in the findings from our survey and focus groups.

Right Chair Right Time Right Now has provided a basis on which NHS England could form some priorities and actions regarding improvements to wheelchair services, including:

- Introduction of a dataset<sup>11</sup> which collects information about the activity of wheelchair services. Data is collected from commissioners on a quarterly basis about wheelchair services and delivery of the wheelchair pathway. The purpose of this collection is to improve outcomes for wheelchair users, and for benchmarking and improving commissioning.
- Model Specification for wheelchair and posture services<sup>9</sup> (see next section).
- Support for CCG's to introduce and develop personal wheelchair budgets.

**2013: NHS Calderdale, Greater Huddersfield & North Kirklees CCGs Wheelchair Services Engagement Report (Appendix 11)**

**2017: Healthwatch, Feedback on Posture and Mobility Services provided by Opcare (Appendix 1)**

**2017: 'Wheelchair Services' Report of Findings - Engagement September - November 2017, CCG (Appendix 2)**

The themes from the three local reports above reflect the findings from the surveys and focus groups.

In addition to these reports, further investigation has been carried out regarding the importance of postural support and care.

*Postural care is about using the right equipment and positioning techniques to help protect and restore body shape - With appropriate postural care and support, distortion of body shape is not an inevitable consequence for people who have difficulties varying or controlling their position.*<sup>6</sup>

*It's never too late to start protecting someone's shape. Failure to protect body shape can have serious consequences for a person's health. It can even cause premature death.*<sup>7</sup>

An investigation took place in 2013 regarding premature deaths of people with a learning disability (CIPOLD). Amongst other things, it established a link between failure to protect body shape and premature death. A Government recommendation which came out of that report stated *CCG's must ensure that they are commissioning sufficient and sufficiently expert preventative services for people with learning disabilities regarding their high risk of respiratory illness. This would include expert, proactive postural support.*<sup>8</sup>

Following on from CIPOLD, the Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. The programme is led by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

Factsheet 21 of the LeDeR Programme<sup>6</sup> discusses the fact that children and young people who have profound and multiple disabilities or physical impairments which restrict movement are at increased risk of body shape distortion. *This can result in postural problems resulting in hip dislocation, scoliosis and pain and lead to difficulties with breathing, eating, drinking and digestion. Changes in chest shape can exacerbate existing difficulties with swallowing and could increase the risk of aspiration leading to respiratory infections.* It refers to the fact that postural care support should be provided on a 24 hour basis (which includes provision of appropriate wheelchair, seating or positional supports).

Recent survey findings into wheelchair services, national and local, indicate that posture related health issues are common to all groups, not just those with a learning disability. Many respondents in all surveys have discussed pain, ongoing discomfort, pressure sores and the lack of timely response to or support for these issues. People without learning disability are more able to articulate the problem (local evidence suggests however, that this may not always lead to prompt action to redress the issues). The Right Chair Right Time Right Now report specifically describes the cost to the NHS as a 'shocking waste of public money' and acknowledges that they are causing harm by providing ill-fitting or ill-equipped chairs.<sup>5</sup>

## Model specification for wheelchair and posture services

As a result of the wheelchair summits in 2014, NHS England in conjunction with stakeholders developed a model specification for wheelchair and posture services<sup>9</sup> which *sets out the ambitions for excellent wheelchair service and provides CCGs with a framework for them to use with their services, providers and suppliers to commission services that meet the needs of wheelchair users and their families.*<sup>6</sup>

The model specification is not mandatory but has been developed as a support tool for commissioners.

The scope of the document discusses why improvements are needed to wheelchair services and the impact of not getting it right which are described as:

*If the service user gets the wrong wheelchair or it takes too long to get them the right wheelchair, this can have a huge impact on:*

- *The clinical outcomes of the Service user*
- *The social outcomes of the Service User*
- *The health and wellbeing of carers*
- *The economic costs of additional services*
- *On-site repair teams should also be mobile and able to visit service user to repair wheelchairs*
- *Service users to be able to give feedback and be involved in the evaluation*
- *After care and follow up and renewal of equipment once it has been provided*
- *Ability to trial the wheelchair before being issues with it formally*

It goes on to describe a person-centred service which mirrors the findings in the current survey.

- *Service users, their families and carers have more choice and control over their wheelchair and associated equipment*
- *Services have a wheelchair which allows them to be as independently mobile as their condition allows and take account of social, educational and employment needs*
- *Service users have a choice of clinic times and locations thus providing more flexibility to fit in with their lifestyles*
- *The wheelchair allows users to interact with their able-bodied peers, engage in recreation and maintain a healthy lifestyle and prevent secondary health problems*
- *Service users feel they have an equal chance to contribute to society and enjoy the physical and mental stimulation that this can provide.*

Finally, it recommends that users of wheelchair services and their carers be involved in *the development of local specifications to ensure services meet local circumstances and need.*

The document can be found at Appendix 13

## **Right Chair Right Time Right Wheelchair Charter**

The Right Chair Right Time Right Now e-digest suggested actions to support desired improvements of wheelchair services. One of the them was the creation of a Wheelchair Alliance to help promote a collective response by all stakeholders. The Wheelchair Alliance was created in January 2015 under the leadership of Baroness Tanni Grey-Thompson and is a campaigning group to help to get a better deal for wheelchair users. One of their actions was to create a Wheelchair Charter<sup>10</sup> which can be seen at Appendix 13.

The Charter sets out very clearly a set of 10 principles closely aligned to the findings identified in the survey:

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 the service via referral from an appropriately skilled professional
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.
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 back-up provided to national 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 ongoing development and training.
10. Supporting clinicians, manufacturers and independent organisations working together to develop innovative, affordable products and solutions.

Signing up to such a charter (as an organisation, service user, provider, commissioner etc) will demonstrate commitment to better services and an improved quality of life for wheelchair users. Document can be seen at Appendix 14.

## Conclusion

1. Key themes identified by the online survey and meetings with regard to Question 1: What would a good Service look like to you? And Question 2: What changes do you think need to be made to the service you currently receive?

User Involvement	Repairs	Maintenance
Equipment	Referral	Assessment
Communication	Clear Pathway	Timescales
Training	Information	Advice and Support
Location	Organisation and Ethos	Sufficient Funding

These findings resonate with previous local and national findings which helps to reinforce their validity. These themes all contain several strands which could be included in the principles of a Wheelchair Charter (Appendix 14) A number of these strands which relate to current service difficulties are already being scrutinised as part of a service improvement plan by the CCGs, eg. Waiting times, communication issues. All strands could be included in the service specification as demonstrated by the Model Wheelchair Specification (Appendix 13).

2. Key themes identified by the online survey and meetings with regard to Question 3: Do you think CCG's could spend their money more effectively?

CCG Performance, monitoring and accountability (accountability was also alluded to in Question 2)
Funding (at each level)
Personal Budgets
Cost Saving and Efficiency
User Involvement

Respondents highlighted current and future service monitoring and accountability of all parties to ensure that the service delivers in the way that it should, and that the current crisis does not recur. The introduction of National Wheelchair Data Collection<sup>9</sup> should assist this function. Performance should be measured from both a commissioner and service user perspective including waiting times and product suitability<sup>3</sup> and a clear complaints system is needed. Learning needs to be taken from service user feedback including complaints.

With regard to funding at each level (clinical model), the survey was not conclusive. A small majority of respondents were clear that funding should be available at all levels and no-one who needs a wheelchair should be disadvantaged. A lesser number of respondents took the opposite view and a further group suggested means testing (some of the comments were aimed at all levels, not just low). There was also a suggestion of refurbished equipment going out on loan which may suggest that this was preferable to charging people. Equally, respondents were keen to recycle and re-use equipment. However, a significant number of people were unable to comment as they did not have enough information or understanding.

Many respondents suggested that the spending across the service should be proportionate to the needs of the client base, with emphasis on the most complex users.

Personal Budgets: some respondents were pro personal budgets; some were cautious suggesting that they may represent a “back door” cut or negatively affect their overall personal budget package. People were positive to the idea providing there was a clear and transparent process and it would not be arduous for users to administrate. Many knew nothing about either vouchers or personal budgets so were unable to comment. However, NHS England requires that CCG’s must develop a personal health budget offer which should be published during 2017/18. It was suggested that services users co-design the offer.

Cost saving and efficiency: Many respondents commented on ways that this could be achieved, and the CCG is already looking at service improvement areas which should contribute to this. An overall approach to effective planning, quality equipment, reduced waste, and getting it right first time was suggested together with recycling equipment. Adequate funding in the first place was referred to, as well as whole systems working and joint commissioning.<sup>1</sup>

The survey results show that user involvement is very important moving forward (from the perspective of local respondents and good practice). This is validated by national data. Service users are keen to get involved and it is essential that the CCG take every opportunity to involve service users in a more meaningful and inclusive way than previously, including co-design of the service and co-production of the planned new service specification. Whilst energy was very high at the events and meetings and people felt very positive about the engagement, there was an underlying feeling that they’d all been here before and that things need to change this time. Momentum has been built up and can’t be lost.

3. More research is available about the importance of postural support, and the implications of a lack of support, including pain, exacerbated health conditions and premature death. This research and the Right Chair Right Time Right Now e-digest allude to the cost to the NHS of lack of postural support and badly fitting chairs. This should be taken into account when considering the funding for the service. There is scope to include this in the new service specification.
4. NHS England are committed to significant improvements to wheelchair services nationally following the Wheelchair Summits in 2014. Areas for improvement have been identified and a model service specification has been drawn up for use as a base by Clinical Commissioning Groups as well as the introduction of national quarterly datasets.
5. A Wheelchair Charter exists to confirm commitment to key principles identified for wheelchair improvement, including the involvement of wheelchair users in the co-design and co-production of the service and specification.

## Recommendations

No timescales or order have been applied as PCAN is not aware of current CCG activities, resources, other priorities and deadlines. Statutory timescales and current service improvement work may influence when recommendations are carried out, for example Personal Budget work is a priority for the CCG, and the service specification will need to be developed in time for the tendering process.

Assumptions:

- Sufficient resource from CCG, appropriate CCG staff time and service user involvement at all levels
- An ethos of co-production, not just involvement
- Consider best practice from other areas
- Service user working groups to be as representative as possible
- All strands of work to be solution focused and forward thinking
- Recommendations are from a service user/carer perspective
- CCG colleagues to devise a plan of action with timescales

1. The CCGs sign up to the Wheelchair Charter or co-design a local one with service users and carers to confirm their ongoing commitment to service improvement and an ethos of co-production with wheelchair users, carers and other stakeholders. Not to be used as a one-off document to win hearts and minds but to measure ongoing commitment of the CCGs by wheelchair users and stakeholders.

2. The CCGs commission a group of service users who are representative of the local communities and current patient population to support the recruitment of stakeholders for the various working groups needed, and to co-ordinate/oversee the various strands of work. This can be a new or an existing group.

3. Organise a “shared vision” awayday facilitated by the above group to agree ways forward and recruit interested people (in the spirit of true co-production).

4. Working groups of interested wheelchair users, carers and stakeholders to be established to work in co-production across the various strands of work below:

4.1 A review of the provider’s website and information provided for patients and professionals to be carried out in conjunction with the provider. This to include information about referral, the service offer, any information about pathways, repairs service and users’ responsibility with regard to equipment. Joint creation of new materials as identified by the review. A leaflet on how to give feedback or make a complaint would be useful (based around the new NHS Ask Listen Do project).

4.2 Current package of training for wheelchair users and carers to be reviewed in conjunction with the provider and adjustments proposed to meet people’s needs.

- 4.3 Engagement carried out with service users and carers to find out what type of advice and support they would like to see (including signposting to support).
- 4.4 Development of staff training to be developed and delivered by service users and carers to share lived experience and to promote greater understanding and empathy of staff.
- 4.5 Service users and carers to explore how they could be involved to offer a regular voluntary service.
- 4.6 Service users and carers to create a checklist for a person-centred, holistic assessment in conjunction with clinical staff.
5. The CCG continues with current service improvement plan informed by the findings of this survey and informs stakeholders of progress made on a regular basis.
6. A review by the CCG and provider of equipment currently issued including engagement with users and carers of that equipment regarding its quality, reliability and comfort.
7. Identification of all patients who have old chairs due, or overdue for replacement so that review can be organised and equipment replaced as needed.
8. A full review by the CCG and provider of how repairs and stocking of spares is currently carried out to determine how an efficient, cost effective 24/7 service could be provided for all wheelchair users regardless of how their chair was funded. Resulting proposals to be shared with wheelchair users and carers for sign off.
9. Provider to propose a system of ongoing maintenance and safety checks to be agreed with CCG and wheelchair users and carers.
10. Working group of interested wheelchair users, carers and stakeholders to review the model service specification and to create a new one for Calderdale and Kirklees. Users and stakeholders to be involved at every level in a true spirit of co-production. To be supported by the CCG and commissioned group (as described in (2) above).
11. Creation of pathways and associated timescales for each level of the service, and possibly for different groups of people, eg. Children and young people by the CCG and current provider, in conjunction with wheelchair users and carers. Pathway to be from point of referral to delivery of equipment + ongoing reviews and safety checks + replacement of equipment.
12. Appointment system to reviewed and revised so that people can be seen outside of office hours and at weekends. This to include clinic times and opportunities for off-site clinics at a range of different locations including schools, and health centres.
13. Current provider to carry out learning needs analysis of all staff and create a training matrix for all levels of staff. Must include up to date training around postural support, customer care, communication and listening skills, disability awareness, and training from service users and carers as described in (3.4) above.

14. Working group of wheelchair users, carers and stakeholders to determine a proposal for the introduction of personal budgets and to develop user friendly information in conjunction with CCG colleagues. (link up with the Lived Experience Lead for the Personalised Care Group at NHS England).

15. CCG to carry out pilot scheme using Personal Budgets to evaluate and refine the proposal.

16. Further discussion about the clinical model and using the findings of this engagement to explore different options (for example a stock of loan chairs).

17. Commitment by the provider (current or future) that they are an equal opportunities employer and develop relevant paid and volunteer roles for wheelchair users and carers to support the delivery of the service.

It would be great if the CCGs could aspire to creating a service which could be a model for other areas to share. Or as one of the respondents said “be a beacon of excellence”.

PCAN, August 2018

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