

## Wheelchair Users Forum

**5th November 2020**

Zoom Meeting 1pm

### Minutes

#### Present

TH	Tony Honour	Independent member
SHo	Sue Honour	Independent member
BC	Bianca Cotterill	Independent member (Pinpoint)
PH	Paul Homeward	Independent Member
JM	Jason Merrill	Family Voice
WTC	Wendy Taylor-Creek	Independent member
LL	Laura Lewis	Independent Member
LO	Liz Owen	Ehler-Danlos Syndrome group
ES	Emily Sibthorpe	Little Miracles
AR	Asta Remezaite	Family Voice
MK	Michelle King	Little Miracles
SH	Sue Harris	Partnership & Engagement Officer AJM Healthcare
GL	Graham Lewis	Healthwatch
DD	Debbie Drew	Healthwatch
DWD	David Wales-Durrans	AJM Healthcare
RV	Roger Valentine	PIN officer
MT	Mark Taylor	C City Council/ Disability Cambridgeshire
HM	Helen McPherson	CCG

#### Apologies

GE	Guy Etherington	AJM Healthcare
SF	Stephanie Ferguson	Customer Service Manager AJM healthcare
SP	Sandra Pedley	Contracts Manager, CP CCG
AM	Alek Mecan	CCG
JS	Jayne Sanford	AJM Healthcare
VH	Victoria Holden	Independent Member

**1. Welcome-** Introductions were made and Graham explained that the meeting would be recorded for purposes of minutes.

#### **2. Minutes of previous minutes and Action Log**

Minutes were approved.

Action 27- discussions are taking place and as people are now seeing consultants

again, this should improve.

AJM are looking at the offer made for maintenance costs offered across the country and they are in the mid-range

Action 30 completed

Action 31 Graham shared some information with Sue.

It was wondered if Everyone Health might like to come to the forum and tell people what they have on offer.

**ACTION** DD or GL to have a conversation with Everyone Health to see what they may be able to offer to wheelchair users and if appropriate invite to a future forum.

### 3.Recent experiences.

After a move from Oxfordshire where a child with cerebral palsy was entitled to a wheelchair, needed hers adjusting as she had grown and needs a new cushion. Parent was told that as the child can walk a little bit at home, she is not entitled to have a wheelchair and thus AJM could not adjust or provide cushioning. The child needs the wheelchair for outdoor use.

DWD The CCG have drawn up the criteria for this area and the CCGs across the country do vary. We do signpost people to charities who could provide the monies needed.

SH The CCG are reviewing the criteria and Sue is part of the panel meeting later in November. This meeting may result in the criteria being adjusted and then AJM would be able to restore some of the service required.

Is this something Healthwatch could escalate up?

SH There is a national campaign by Tanni Grey-Thompson.

**ACTION** SH to share the details

It was noted that sometimes there is disparity within the county too

SH Suggested this is because the assessment is based on the day someone was assessed. There is a review process and review criteria too.

An assessment had been done for someone who felt under pressure to accept a certain type of chair.

They are getting a chair with the personal budget route. The cushion that was needed was ready so they received a call saying they would be delivering the cushion and taking away the old chair- however the budget for the new chair had not come in. This person has been left with no chair since 12<sup>th</sup> October and has been sat an office chair around the house.

DWD This should never have happened-

**ACTION** DWD to investigate and speak with the individual outside the meeting.

Someones partner who has been a chair user since 18 yrs old had a visit re their electric chair which they use when out and about. They use a manual one in the house but are unable to go far as they have not got the strength. They have been told they are not entitled to the electric chair and AJM would like to take it away.

It would be good to see the contract with the eligibility criteria on it -would this be possible?

**ACTION** GL to discuss with AJM

BC Who employs the clinicians is it the CCG or AJM?  
DWD AJM

#### 4. Service User Guide- Sue Harris

A copy of this was shared with the papers for the meeting. Sue said to ignore the photos as they would be changed but she was wanting feedback.

There is an audio book being done and an Easy Read version too.

Email or ring Sue with comments before 20<sup>th</sup> November.

**ACTION** GL to share with the Physical Disability board too for them to make comment if appropriate.

#### 5. Experiences of Transition

Bianca - Whilst living at home daughter went to special school which had a therapy unit. The school had a designated physio who knew the students well. They were connected with the wheelchair service and any issues with the chair were sorted by the physio. The physios had a lot of experience of wheelchair use and management and they were also able to help with the assessment process. Whilst living at home I was able to ask for support for her and the respite service were also were knowledgeable about wheelchair use.

Now she does not live at home but is still in education- there is no allocated physio and does not have access to one. They are then dependent on care staff having knowledge and they are not taught about wheelchair use so knowledge gets passed from one to the other. My daughter still needs someone who can speak up for her and recognise when adjustments etc need making so the onus falls onto the family. Not everyone has family and certainly as that person gets older family may be unable to keep up the responsibility.

Daughter has a motability car too and family have had to teach staff how to safely clip the chair in.

When people go from child to adult services a lot of what they were eligible for is no longer available.

MK In Peterborough we managed to get MIDAS training for people- Michelle has shared this.

With the Midas training the lady who attended the first hour for me is also a carer who has MIDAS training if its helpful this is what the training covers and she takes people out in their mobility car it was funded from a clients direct payments as part of a care package

#### Module A: The role of the Passenger Assistant

This is the foundation module because it is a starting point for further training. It covers the role and responsibilities of a Passenger Assistant, including legal, practical and safety issues.

#### Module B1: Assisting passengers with disabilities

This module includes general disability awareness and passenger assistance techniques.

Module B2: Assisting wheelchair users who travel in their wheelchairs

This module includes boarding and alighting using passenger lifts or ramps and assisting wheelchair users to travel in their wheelchairs.

Module C1: Supervising children and young people with special needs.

This includes supervising children and young people with learning difficulties, autism, physical disabilities, sensory restrictions and emotional or behavioural difficulties.

Module C2: Working with adults who require care and supervision

Similar in content to Module C1

Michelle King spoke to families and they expressed similar issues to Bianca. They included

- Lack of relationships ie knowing the workers
- Health and safety focussed not what the person wants
- Adults with communication needs not being able to express that they are uncomfortable.

An example of a problem is that a child who had previously had a moulded seat was told that there is no funding for this for adults. Unless the adult is still in education where some needs can be accommodated under the Education Health Care Plan monies for funding the seating needs to be found from elsewhere.

BC Adults with learning disabilities are dependent on relatives acting as project workers because relying on social care is not satisfactory.

**ACTION-** GL to discuss this at the Carers Board and possibly the Physical Disability Board.

BC There is a “Preparing for Adulthood” which is in draft at the moment but having looked at it there is only 3 pages dedicated to health.

QU is this the same as the one from Peterborough?

**ACTION** BC and RV to send GL the respective leaflets to see if they are the same.

**Next Meeting 8<sup>th</sup> February on Zoom 11-1**