

# Mobility Challenges & Opportunities Report

Edition 2



## **Mobility Challenges & Opportunities Healthwatch Bury Report 2017/18**

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## Executive Summary

Healthwatch Bury undertook a piece of qualitative research to explore the issues and concerns affecting people living in Bury with mobility impairment. Healthwatch completed one to one interviews, met with two local groups and promoted a survey across social media channels.

We asked people to tell us about:

- i. The assistance they have to enable and support their lives (such as family help, Personal Assistants, friends, living in a residential setting or the care agency)
- ii. Their experiences of finding and accessing community groups in Bury
- iii. Their experience of finding and accessing paid support and additional funds
- iv. Their experiences of health and social care
- v. Changes they would like to make to health or social care services
- vi. Concerns around wheelchair services
- vii. Their experience concerning access issues

The key messages were:

- Most rely on support from family and friends with many acting as carers.
- Personal assistants are key to help people remain independent but keeping and finding the right PA is not always easy.
- Access to suitable transport is important to help them maintain their independence but access issues and costs are blockages.
- Concerns about Ring and Ride and taxi access.
- Access to local groups and social interaction is important but many don't know where to go although those that do find them invaluable.
- Accessing funds and benefits is a constant round of assessments and reviews.
- Finding information and the ability to challenge funding decisions related to care, is difficult.
- Access to adaptations to help people remain independent takes too long.

- About half of the respondents did not feel involved as much as they wanted to be in discussions about their healthcare.
- There is a need for greater empathy concerning disabilities, through improved disability awareness training across health and social care. Services should be co-produced and developed alongside mobility impaired service users.
- Around a third of wheelchair respondents had no concerns about the repair service but half had found the service difficult to access and waiting times are too long.
- The need for improved mobility friendly public transport and access to facilities is required.

Healthwatch Bury have suggested a number of recommendations which have been agreed following discussion with an advisory group made up of mobility impaired service users. These may be found on page 33 of the report.

## **1. Context**

Having a good quality of life and being able to remain independent is understandably important to those living with any disability impairment. However, despite numerous policies and initiatives over the last decade disabled people are still facing an uphill battle to get the help and services they need to be able to do this.

This report stems from a number of concerns which Healthwatch Bury received from people with mobility disabilities. As these were quite diverse issues Healthwatch Bury wanted to identify the main challenges and to explore potential opportunities to improve the services available. The issues and concerns raised through the feedback are summarized below.

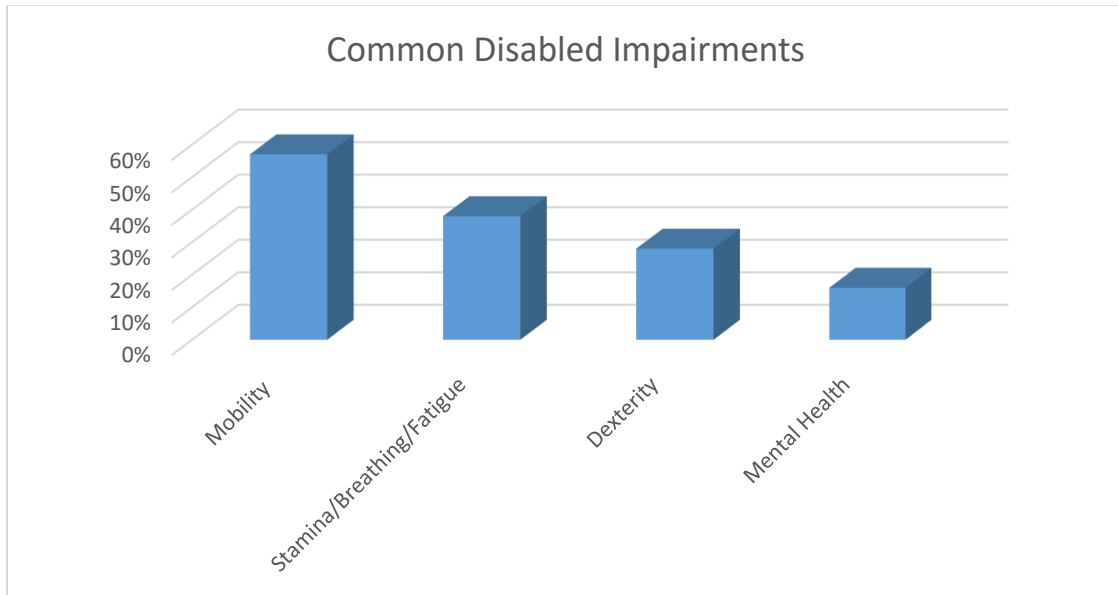
## **2. Mobility Impairment**

Mobility difficulties may be due to a congenital conditions such as cerebral palsy or through injury or conditions such as multiple sclerosis. Other hidden conditions such as heart and lung disease, cancer or epilepsy may also impact on balance and create mobility issues. But all these conditions will impair a person's strength, manual dexterity, coordination and ability to walk.

According to the Department for Work and Pensions<sup>1</sup>, the highest common disabled impairment which had the most impact on daily life was mobility. The table below outlines the top four:

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<sup>1</sup> Work and Pensions, July 2014, Family Resources Survey



The impact can be seen from the 2011 Census for Bury which stated that 9.5% men and 9.8% women (22,000 adults) reported a disability that limited them a lot in their daily activities.

### 3. Methodology

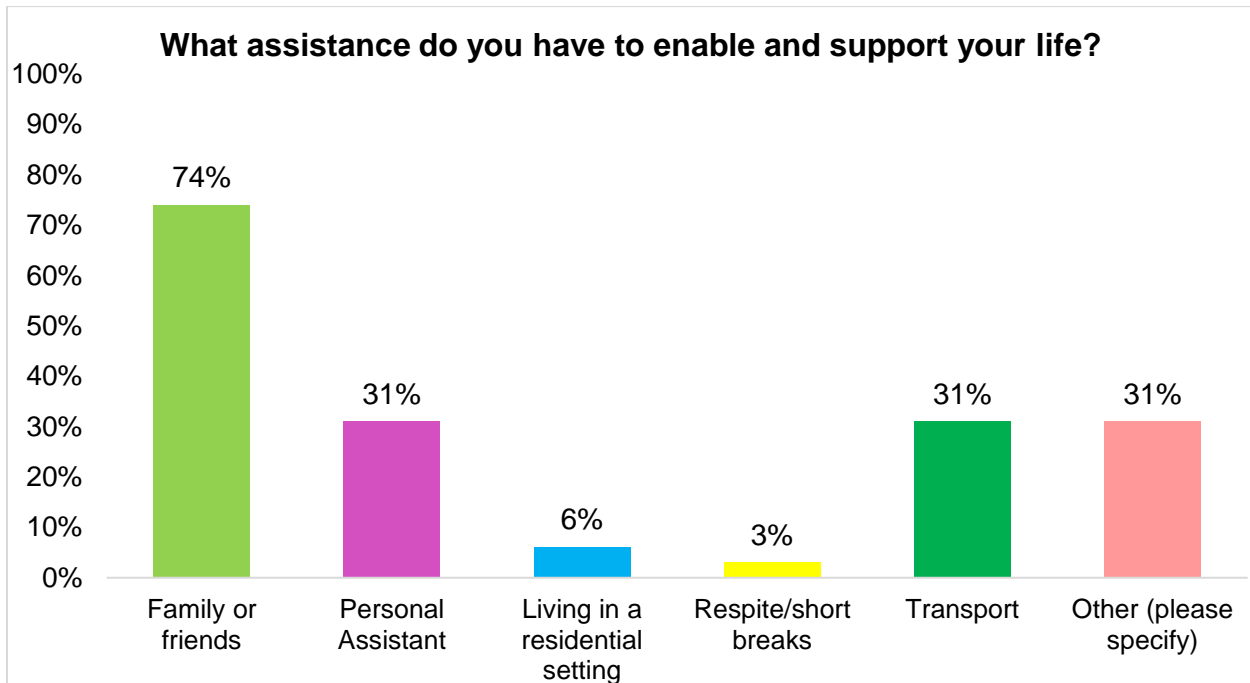
Healthwatch carried out qualitative research through a number of channels:

- Six one to one interviews with service users
- A survey distributed via social media sites, third sector organisations, service user groups, libraries, mobility shops and Bury Market, with 33 responses received
- Group meeting with the Bury Multiple Sclerosis Group and Bury Red Rose (over 60s group).
- Bury Citizens Advice Service - case studies and research data
- Findings and recommendations discussed and developed through an advisory group made up of Healthwatch staff and three service users

## 4. Key Findings

### 4.1 Assistance received

The table below outlines the assistance people are being given to enable and support their lives.



It is evident from the table that the majority of people rely mainly on family and friends, personal assistants and suitable transport. A number of respondents stated they don't receive assistance from anyone and others referred to carers, support from private agencies and community care. The following section describes in more detail the feedback from the three main areas.

**A) Family & Friends – 74% (26)** of the respondents stated that family and friends provide them with assistance to enable and support their lives:

*“At the moment, I rely on the assistance I receive from my parents and PA’s to enable and support me in my life.”*

*“My family are really helpful as far as our finances work and have helped us out in the past by contributing to pieces of equipment and other costs. The cost of our care is not fully met by our budgets and we contribute to those costs considerably each week.”*



*“Daughter is my carer”*

*“My wife is my carer and provides me with assistance”*

*“I value spending time with my friends at the centres and with my brother who is my main carer”*

Several people said that they have carers visiting several times a day. One lady said she would like to find out if she is eligible for any additional support, as she currently relies on her daughter but doesn't know how to access extra help (Healthwatch provided her with the details).

It is worth noting that there are around 1.2 million wheelchair users which equates to about 2% of the population and, of those, only 28% are under the age of 60<sup>2</sup>. These figures, alongside those of the other disabilities and an aging population place a huge demand on the system making the carer workforce more important than ever.

There are already several well established carer support organisations in Bury e.g. Bury Carers Centre, Crossroads, Making Space and it is important to continue promoting their services to ensure continued support for both the carers and those being cared for. It is helpful that the Locality Plan recognises the valuable role played by the people in Bury who provide unpaid care. The proposed establishment of a 'New Deal for Carers' will help ensure support is provided to carers across Bury.

**B) Personal Assistants (PA's)** - 31% (11) of respondents receive help from their personal assistants.

The Care Act 2014 (that came into force in April 2015), placed the legal duty upon local Councils in England to provide or arrange services that promote independence for disabled people. Councils are legally obliged to offer a personal budget to anyone eligible for social care funding.

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<sup>2</sup> Economic & Research Council, Shaping Society, 2014

This is often used to purchase services from care providers or to employ a personal assistant (PA). It is important to remember, as the direct payment holder, the disabled person becomes the employer and is responsible for all the legal, financial and practical issues that entails. Most employ a management service but for those who don't and want greater control over their lives and a choice of PA's, there are a number of concerns:

- **Learning to be an employer** - The feedback we received indicated that this requires the personal budget holder to learn a whole new skill set which includes recruitment and interview techniques, an understanding of how to meet the training needs of their PA's and employment and pension rights.

Having the right support in place or receiving advice on managing personal budgets appears to vary as the comments we received show:

*".....the associated services and processes, such as employment advice, payroll and recruitment services, to be problematic, as they are somewhat ineffective, inadequate and/or inefficient."*

*"...the form used in Bury makes the assumption you will be using a management company. It isn't designed to allow you an alternative option. It takes away the freedom of choice and therefore contradicts the Care Act 2014."*

*"...The payroll company doesn't work well which we don't want for our personal assistants as at the end of the day they want to be paid."*

- **Finding and attracting the right PA** - An important factor is the ability to find the right PA, especially as they will often be required to provide personal and intimate care from the start of their employment. From the feedback and survey responses received about PAs, attracting the right calibre of applicant on the salary available to them to offer, was difficult. The feedback from our interviews was that service users felt they weren't able to offer a high enough hourly rate to attract enough applications from an already small and competitive pool of potential candidates. The

survey responses also highlighted the issue of benefit reduction which means less available funds and therefore hours adding to the difficulty of hiring and keeping PA's.

- **Offering an attractive salary** - The difficulty of being able to offer a competitive living wage was also highlighted as an issue. The ability to offer good candidates a rate commensurate to the skills and tasks required is difficult under the current financial structure. The offer for PA's tends to be a lower hourly rate, even when the person's individual needs are more complicated. In some instances the disabled person described how they have to supplement the hourly rate in order to find or keep good PA's, which often means needing financial help from family or friends.

This makes it harder for local people to attract local carers as, understandably people will apply for positions that pay more. Providing support to finance an appropriate hourly rate that is based more on the need and expertise required of a PA, would help stimulate the market and create a fairer playing field across GM. This approach would also attract more skilled people into the profession, helping to make the service a more viable and attractive career.

The view was expressed through our interviews that the promotion of the PA role as a 'serious and viable' career and raising the financial rewards, would go a long way to growing and attracting a stronger local workforce.

Feedback from the interviews highlighted the difficulties in getting holiday and sickness cover for PA's with limited options available. The view was expressed that the majority of people have to rely on family and friends to step in.

Financing an agency to provide cover is also problematical and administratively complicated, with high charges also being set by the agencies (£17:50 per hour was quoted by one respondent as the hourly cost charged by an agency for PA cover). It is a requirement of the Council for both the agency and any use of a person's contingency fund for cover, to be approved by a panel, adding additional stress to

the situation. There was clearly some frustration about the constraints placed upon people when they need to get cover quickly.

It was also highlighted that for those with multiple health and care needs finding someone with the right skills and expertise who is available at short notice, is extremely difficult. Although the introduction of personal budgets has enabled service users greater independence, the market place and available workforce is not always able to match the demand or needs of those with disabilities, particularly those with complex needs.

Similar results to those provided by Healthwatch were also highlighted in recent research by Skills for Care<sup>3</sup>:

- Constraints associated with funding and pay and the low pay rates deter better qualified staff and staff best suited to meet complex needs
- Issues relating to pay were closely linked to the hours people need and for those requiring fewer hours of support (particularly at unsociable times) it is difficult to find people to take on the role
- Difficulties in matching staff to meet specific care or medical needs

➤ **Concerns regarding restrictions and lack of flexibility for how a personal budget can be used were raised.** The following quote sums up the predicament:

*“Sometimes, I find the prescriptiveness of my personal budget’s support plan to be problematic, as I use all my allocated care hours for their main prescriptive purposes and functions (including time of delivery. It can be difficult to use the allocated care hours in a more organic and flexible manner, if they are required outside the usual hours when support and care is normally delivered.”*

This research also highlights the fact that for those who are heavily reliant on their PA, it is all about managing their daily lives around the PA timeslots and within a finite budget. They are constantly juggling what they are able to do and when (which included taking time to meet and talk to Healthwatch). Everything revolves around

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<sup>3</sup> Skills for Care, Recruitment and Retention in Adult Social Care: Secrets of Success, May 2017

their support network and what they can afford to cover within their budget, often meaning that they cannot take up any new opportunities or social events leaving them feeling that they are existing rather than living.

**C) Transport - 31% (11) of respondents receive support with regard to transport.**

Transport was an area of key concern to respondents with a number of issues being raised:

- **The Ring and Ride Service and cost of accessible transport -** Some respondents voiced concerns about the quality of the service for instance, people described issues with the timing of the pickup and the impact that has on their lives when the bus is late, other people feel the drivers do not have enough local knowledge.

*“It’s access to transport that is so difficult with Ring and Ride being so problematic. You have to keep re-dialling. Some people won’t be able to get to some places. If I have had to use taxis I have had to spend £28 in four days, including a £19 fare when ‘Ring and Ride’ couldn’t take me home. It can be £11/£12 an hour for a taxi. They’ve cut back on the service (‘Ring and Ride’); I’ve contacted Andy Burnham, as it’s a service that runs across Greater Manchester. The vehicles are not well maintained. The drivers are polite but they don’t seem to know the Greater Manchester area and they are not allowed to use their own satellite navigation systems. The drivers are fed up too. The booking girls are good but they don’t recognise certain places; I go regularly to the Jubilee Centre but they tried to book me to a place at Droylsden! It can be the scheduling too that causes difficulties. If they don’t know the area it’s difficult for the drivers to work out who to drop off or where to go next and often end up crisscrossing the area. We go to a regular meeting which has an 8 o’clock start time and runs on till 10 something. ‘Ring and Ride’ did use to pick us up at 9.30pm but the last time I booked they wanted to pick us up at 8.20pm which made it not worth going. It’s important that we go out as caring for my husband can be stressful”*

*“There needs to be a review of ‘Ring and Ride”*

*“..its better transport really; there’s been no money invested in ‘Ring and Ride. There’s no depot in Bury now so the local area knowledge is missing. The staff can’t be faulted and they are very polite. Once a journey has been agreed and booked we know they will come for us. It’s the flexibility though and the difficulties in booking that are problematic.”*

*“Another reason I find it hard to leave the house is the transport. Taxis are expensive and people with mobility difficulties can get taxi tokens but it is £10 a month and you have to give up the bus pass but can still use the metro. The metro is no good for me because I have a walking frame and struggle to get about”*

- **Access to the tram system** - A wheelchair respondent described how a journey on the tram can turn into a marathon exercise if the lift at the Bury station is out of order, as they have to go back down the line and get off at Radcliffe, then get a bus or taxi back to Bury.

Another respondent described *“using a mobility scooter on the metro line involves arranging to take a test for the suitability of your scooter and your ability to use it safe”*

- **Lack of suitable taxis** - From 6 April 2017, it was made illegal for taxi drivers to discriminate against wheelchair users. However, it is still a problem, our feedback indicates that the taxi drivers refusal to take wheelchair users, is often due to the design of most taxis and the size of a wheelchair not allowing the disabled passenger to turn round in order to travel backwards in a safe manner that is in compliance with the majority of councils’ licensing policies.

*“....taxi unsuitable for very large wheelchairs”*

*“Better transport, like buses from home and taxis that can take wheelchairs or scooters”.*

- **Transport and the impact of benefit changes** - Many respondents were worried about the changes to the Disability Living allowance (DLA) and Personal Independence Payment (PIP); both important in determining eligibility for other benefits, and in particular, eligibility to the Motability and Blue Badge Scheme. Someone receiving the PIP enhanced level Mobility component is eligible to lease a vehicle under the motability scheme and is exempt from Vehicle Excise Duty on that car. Failure to qualify for this rate of benefit, as a result of reassessment, could therefore mean loss of a car. Loss of the PIP mobility component will also lead to the loss of automatic entitlement to a local authority disabled person's parking badge and a bus pass. Respondents were concerned about the potential loss of these benefits and the negative impact it would have on their independence.

*"I need assurance that I won't lose my motability car when I am reassessed for PIP - this is a big worry for me"*

*'Was initially rejected for Blue Badge - this could have been my fault for understating my disability. I did appeal and then there was no problem qualifying for badge...'*

*"There is a problem with Motability Cars. Whilst you are working paid or voluntary, everything's ok and you are more likely to get a grant. That gives you access to a vehicle. There are lots of people who could get out and get a job but they can't get out as they have no car. You've got to be doing voluntary or paid work otherwise you have to pay yourself. We are talking a lot of money for the vehicles we need. The people from the company who look after your vehicle are really helpful and give you lots of advice."*

- **Mobility friendly public transport** - Respondents expressed the need for improved mobility friendly public transport with more support available to enable them to access public transport.

*"Extra help on a bus"*

*“Help getting wheelchair on and off the bus”*

- **Parking** - Respondents raised concerns about the difficulties and impact of not having suitable disabled parking.

*“Parking facilities for disabled as there aren't enough to be able to get into shopping centre”*

*“I pay for my podiatry needs but as I was late by 4 minutes for my podiatry appointment due to issues with parking and my wheelchair and they refused to see me.”*

*“Parking facilities for disabled as there aren't enough to be able to get into shopping centre.”*

## **4.2 Finding and accessing community groups in Bury**

We asked people to tell us about their experiences of finding and accessing free or community groups in Bury; 42% of people who responded to this question have not used any free support or community groups in Bury. Most of these people said they would not know where to go to find out about these groups. The other 58% have found that attending these groups has really helped them to learn about their condition and is feel it is important for their social life.

Our feedback shows that the service users often find these organisations to be their ‘lifeline’ and an invaluable source for support.

*“Bury Society for the Blind have helped as I am registered as partially sighted. Multiple Sclerosis Group is great for socializing”*

*“I attend Grundy Day Care Centre once a week and visit the MS Society social group once a month”*

*“I go regularly to the Jubilee Centre”*



There are some fantastic local groups which support people with various disabilities and health conditions, for example, Bury Society for the Blind, Communic8te, the Multiple Sclerosis Society, Your Support Matters, Jigsaw and Bury People First but there are limited options for people with mobility difficulties.

There is also a gap in the provision of a support group or forum where people with different disabilities can meet together on a regular basis to voice their concerns and share information about local events and services.

Access to suitable social and leisure facilities is key to ensuring people with any kind of disability maintain an active social life. Leisure facilities that cater for wheelchair users are limited in Bury, for example, Bury Cinema cannot cater for multiple wheelchairs so friends who may wish to sit together and are wheelchair users need to go to other areas as such Bolton, which can cater for two wheelchairs to be sited together.

The negative affect of isolation and loneliness on people is well known, as is the and the importance of social connectivity on a person's wellbeing. People with mobility issues and other disabilities are even more likely to be affected with over 53% reporting feeling lonely. This rises to 77% for young people<sup>4</sup>.

A number of comments were made highlighting problems in maintaining social groups:

*"We don't have any help from any outside agency. Our family lives away and we've lost a lot of our friends; everyone has lives of their own."*

*"...Sadly, I don't have friends who are able and willing to enable and support me in my life"*

*"I enjoy my centre and gain a lot from spending time with friends and support workers. I would be lost if I don't have this paid support."*

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<sup>4</sup> Jo Cox, Addressing Loneliness in Disabled People, 2017

It is clear from our feedback that people rely on the groups for support but there are limited options for the different age groups and needs. Without the facilities and access to leisure and social activities, to enable social interaction, research shows it impacts negatively on people's wellbeing and mental health.

It is important, therefore, to turn this on its head and not look at what can be afforded but to consider the costs on health and social care if support it isn't provided due to the deterioration on people's health and wellbeing and subsequent call on services which may otherwise have been avoided. Local groups however, need the infrastructure and funding security in order to provide and develop the service they offer.

The fact that the Council has recognised the need for a healthy voluntary sector in Bury and is working closely with them, through the newly formed Voluntary, Community and Faith Alliance to look at building the support needed across the sector, is extremely positive.

#### **4.3 Accessing paid support and additional funds**

Having access to the funds to be able to support themselves to live independently is understandably important. The following concerns were raised by respondents:

- **Higher than average living costs** - The difficulty of accessing funds to cover everyday living costs was highlighted as being a struggle:

*“Everyday living costs aren't taken into account with our allowances. If a lightbulb goes I have to have an electrician. .... The cost of disability related needs aren't factored in.*

*.....Social Services don't help or advise if your charges seem higher than average as to whether your charges seem reasonable or if you need to review your energy provider or generally how you can budget your energy costs.”*

The charity Scope<sup>5</sup>, had calculated that disabled people pay an average of £550 per month on extra costs related to their disability. This also means disabled people are

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<sup>5</sup> Scope, Priced Out: ending the financial penalty of disability by 2020, 2014

twice as likely to have unsecured debt totaling more than half their household income.

- **Benefit Process and Assessments** - Accessing funds and benefits for those with mobility impairment and any other disability appears to be a constant round of different assessments and form filling.

*“The way finances work should be looked at; it seems to depend where you live. Continuing Healthcare is a big issue. It seems to work for cases where mental capacity is an issue but doesn’t seem to respond to physical issues. I’ve had 3 assessments and we are waiting for another with the managers. I’ve been told I’m not disabled enough – how much more disabled do I need to be?”*

*“.....I also find the need to repeat oneself in order to acquire and retain the support quite problematic in terms of the associated processes and particularly the number of assessments and amount of paperwork it can involve”*

- **Interpretation and challenging decisions** - Our feedback highlighted that people feel there is a lack of opportunity to challenge health and social care professionals or process, for example, the Bury Resource Allocation System is ratified by computer and does not allow for any deviation from the set options in the personal budget multiple-choice assessment and assumes everyone wants to use a management company to manage their budget.

There is criticism of the processes and the ability of the assessors to properly interpret and convey what has been said and how that affects a person’s needs. This often results in a poorer outcome and less funding for the more vulnerable people.

*“Professionals come and talk to me but then go away and have a meeting without me. Do they have someone on the Bury Council panel who is a disabled person/service user or in a receipt of a personal budget? The record of the panel (minutes) is not available. More information about the panel and process is required to ensure it is a fair and equitable process”.*

There is recognition that not all disabled people whether due to mobility impairments or other disabilities, have the knowledge or feel comfortable challenging the decisions made about their care. Decisions are made by panels for such benefits as Personal Budgets and Continuing Health Care without the client being present, making it difficult to answer any queries or to challenge decisions made. Independent advice and access to support from people who understand their condition is considered key.

One respondent recommended the '[Problem-Solving Toolkit](#)' (2016) produced by Cardiff University and the charity Cerebra. This toolkit aims to support disabled people and carers who encounter difficulties with statutory agencies in relation to the provision of health, social care and education. It provides template letters and advice about how to handle different situations they may find themselves in.

➤ **Disability Living Allowance (DLA) 'v' Personal Independence Payment (PIP)**

Bury Citizens Advice have discussed with Healthwatch Bury, their concern regarding the assessment process; in particular the Personal Independence Payment (PIP). This was previously the Disability Living Allowance (DLA) and like the DLA the PIP can be claimed by people under 65 who need additional help or supervision or have moderate to severe mobility problems.

Recent Citizens Advice research<sup>6</sup> highlighted a number of issues and stated that more than 85% of people living with a disability or serious long-term health condition, believe their mental or physical health is frequently affected by the stress of being reassessed for benefits.

The report highlights a number of issues and concerns with the reassessment process which mirrors the feedback Healthwatch Bury received, such as difficulties completing a long and detailed application form, mixed experiences of the face-to-face medical assessment (including a lack of transparency by staff conducting the

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<sup>6</sup> Citizens Advice, 'From DLA to PIP – Experiences of clients from across Greater Manchester', March 2017

assessment), difficulties getting to appointments; and concerns that the impacts of fluctuating health problems and mental health conditions are not appropriately recognised.

The Greater Manchester CAB report<sup>7</sup> highlights areas of major concern being:

- The sensitivity, accuracy and probity of the medical reassessment process, which is carried out for the Department for Work and Pensions by private contractors ATOS and Capita. Face to face assessments are widely experienced as medical assessments rather than assessments of functional ability. These concerns have prompted an Inquiry by the House of Commons Work and Pensions Select Committee into the PIP assessment process.
- Emotional distress and embarrassment over intrusive or insensitive questioning.
- Widespread evidence of extensive delays in the reassessment process and difficulties finding out the status of a reassessment claim and the likely duration of any delay.
- Failure to backdate any new, higher award, (for example, in response to deteriorating health) to the date when the increased needs first began. Moreover, payment of a new PIP award is also delayed until four weeks after the DLA payday following the date of a decision on the PIP claim.

The CAB Bury case studies, attached at appendix i, kindly shared with Healthwatch Bury, help show how this issue has impacted on local residents with mobility issues.

The implications of the benefit changes is also highlighted in the Equality and Human Rights Commission research<sup>8</sup> which suggests that the reforms will disproportionately affect disabled people through reductions in income and services, while the transition from Disability Living Allowance to the Personal Independence Payment takes place, could result in a reduced income for many disabled people. It is estimated that in Britain, by May 2018, there will have been a 28% reduction in the number of individuals in receipt of Personal Independence Payment compared to those who would have received Disability Living Allowance.

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<sup>7</sup> Citizens Advice, From DLA to PIP – Experiences of clients from across Greater Manchester', March 2017

<sup>8</sup> Being disabled in Britain, A journey less equal, EHRC, 2017

With Devo Manchester and the coming together of the Local Authority and NHS commissioners there is a real opportunity to review how the policies and systems work and as one person told us:

*“Make them one service to help look at people’s situation in a more holistic manner and, also, hopefully, to stop the need for as many assessments and qualification criteria processes being carried out, as well as the need for repetition. In other words, change/eradicate the inert bad practices of both the Social Care and NHS system and co-produce more with service users.”*

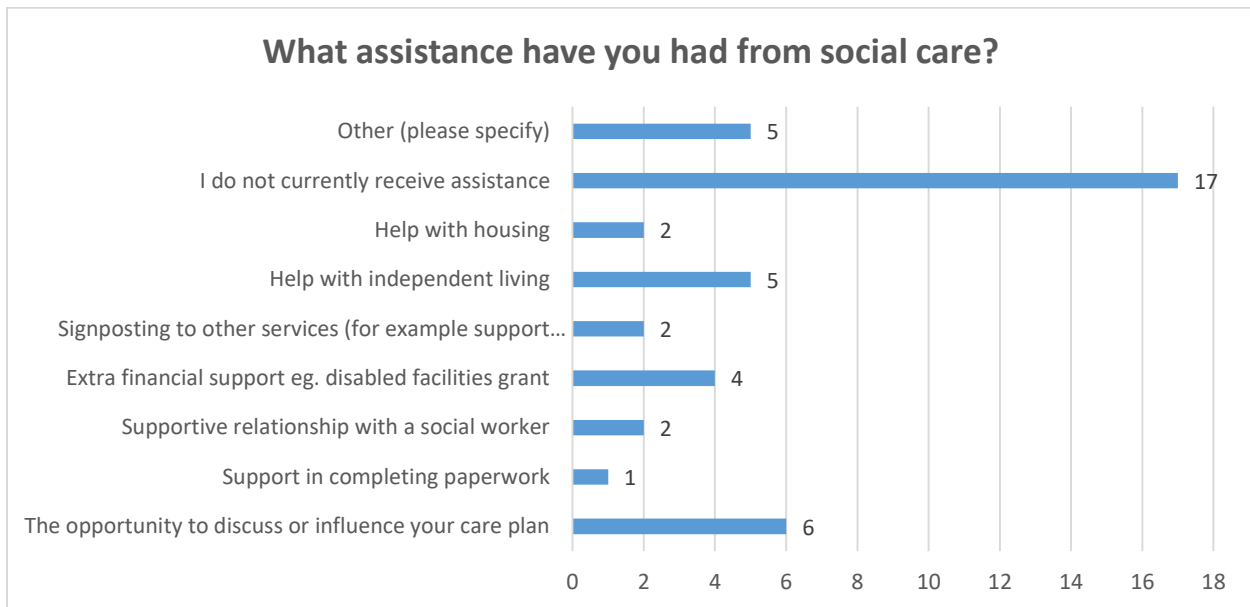
Being able to access and receive the right level of funds is clearly important to enable disabled people to remain independent and have a good quality of life, however, in the current economic climate, with ever tighter benefit entitlements for those most vulnerable in our society, this is an ever increasing challenge.

Our feedback shows that the constant round of assessments and funding applications are highly stressful and often adversarial. Local people would prefer to be able to tell their story just once to empathetic professionals who see the person not just the wheelchair or the disability.

There is an opportunity through the One Commissioning Organisation to bring together health and social care assessments and budgets, reduce bureaucracy and duplication. By coming together, the two commissioning services (Council and CCG) can address the needs of disabled people in a more holistic and sensitive way, thereby providing them with greater personalized care, support, choice and control over their lives.

## 4.4 Experiences of health and social care

We asked what assistance people receive if any from social care:



Although nearly half of our respondents don't receive any social care support (reflecting the reliance on family and friends highlighted earlier in the report) of those that do the following concerns with the assistance they received was raised:

- **Lack of continuity of care** - Respondents highlighted the lack of a personal social worker means clients having to continually repeat their story. The frequent changes in both health and social care staff make it difficult to build relationships and knowledge about the service users' needs.

*“... when something changes, you seem to be allocated someone else. The social worker who knew us and who understood our needs came out to XXX as it made sense to her to do that.....”*

The lack of knowledge and understanding about the individual can also have a negative impact on the persons care plan.

*“... the fact that in Bury you are no longer allocating a social worker for a lifetime does not help with continuity and (in addition to the changes in the paperwork) sees you having to laboriously re-cap or repeat everything frequently. This can be made*

*even more difficult if, following your last assessment, there has been gaps left in your written final support plan, which you often do not see until it has been to Panel, even though you are meant to see it before it reaches this stage and results in a final personal budget amount being awarded. ...”*

- **Adaptations** - Having the right adaptation provided in a timely fashion can enable people to live independently for longer and to be discharged quicker from hospital, but respondents indicated that getting that service is often difficult:

*“My experiences in the past of waiting for adaptations to the house and equipment mean that although I know my bathroom is not meeting my needs, I won’t contact Social Services or apply for a Disability Facilities Grant. It would be too lengthy a process.....”*

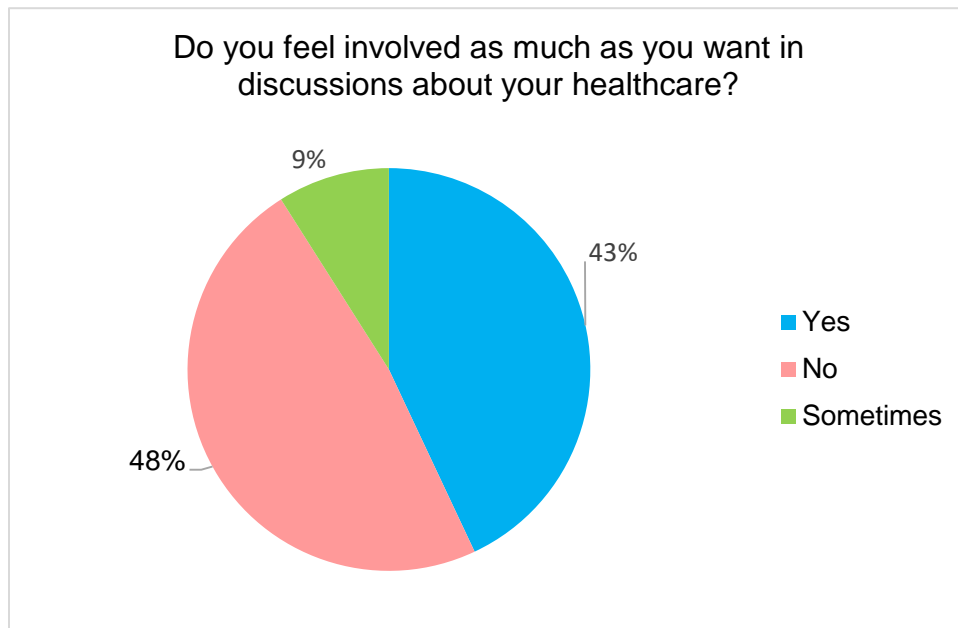
*“More information is needed for people around the equipment they need if they are disabled. At the point where people are told they have a problem that is going to last, even if its temporary, they need help to know what they need and how to obtain it. I see so much money wasted. There is a big vacuum in Bury.”*

*“I’ve recently been in hospital ..... They said I could only go home if I had a hoist due to safety issues. We were told that through a Disability Facilities Grant, it could take up to 6 months to put in place. ....I had one in place then the hospital said they had to check it and train the carers so XXX had to stop in hospital another few weeks.’*

*“They really need to streamline people coming out of hospital. When you are trying to make arrangements and staff are going off for one reason or another or they are changing it doesn’t help. One man on the ward had been in 13months as he needed adaptations to his house and he couldn’t afford for them to be done himself and needed to wait for the care people to put them in place. Pooled budgets need to happen as the cost of keeping people in hospital waiting to go home is substantial.”*



The table below outlines how involved people felt in the discussions about their health care:



Almost half said they didn't feel as involved as much as they would like to be in discussions about their health care and this was highlighted as an area for improvement.

*"I am able to discuss my problems with my doctors. There is sometimes too long between hospital appointments, and you have no one to talk to whilst you are waiting"*

*"Think doctors or hospital should give older people more help and information."*

*"Sometimes and other times goes over my head"*

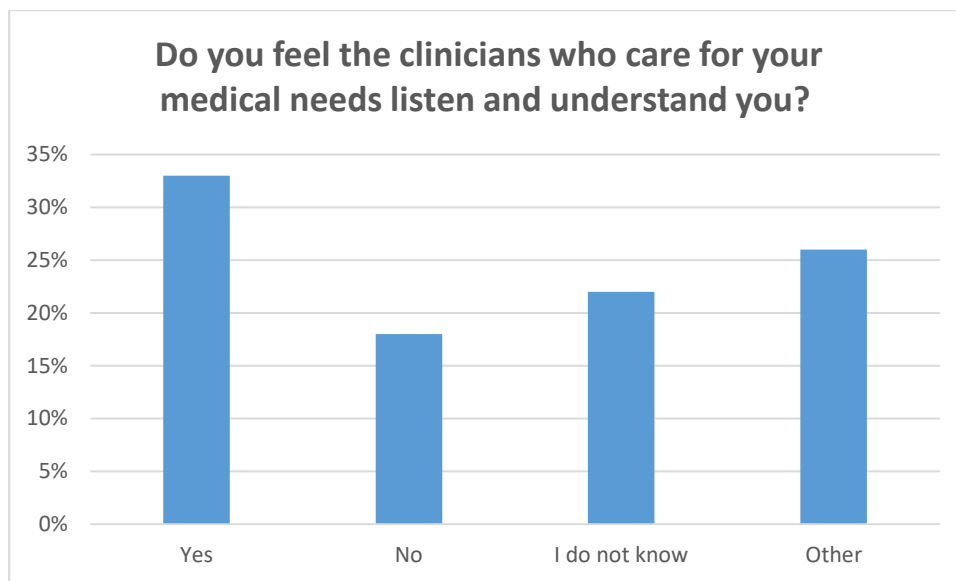
*"I don't feel anyone cares about my healthcare"*

*"No. I have had MS for 42 years, in this time my situation has been reviewed twice"*

*"Yes but more professionals need to be involved and understand the issues that are important to disabled people and people with additional needs"*

*“Yes I feel involved, I may sometimes do not like advice, find it worrying but when it's explained more I accept the advice”*

We asked if people felt their clinician who cared for their medical needs listened and understood them of those who responded:



A number felt it was mixed depending on the clinician. We asked could the relationship with their clinician be improved with more regular contact being the most suggested improvement.

*“... More regular contact and information re: more recent treatments”*

*“...by having more contact for regular assessment”*

One respondent highlighted the problems with the lack of knowledge about his disabilities but appreciated the difficulty in being an expert on his condition was difficult.

*“...as I do not want to be understood solely in terms of my impairment. However, equally, somewhat understandably, he often does not have enough knowledge of my disability/impairment and its associated problems to factor them in to diagnoses, assessments and consultations, often leading to a prolonged process of misinterpretations and understandings”*

One respondent highlighted the lack of disabled facilities in hospitals for those needing a wheelchair:

*“There are no facilities in hospital for disabled people; I was in hospital for 5 months and couldn’t have a shower. Can you imagine the indignity in bed baths for that length of time? It took them 3 months to find a hoist so I could get between my bed and my wheelchair. The ward was grossly understaffed. Often I saw 2 staff trying to look after 25 patients”*

#### **4.5 Changes to health or social care services**

Our respondents told us that improvements could be made to social care by:

- The social worker taking more time to sit down and listen to them and understand their disability and individual needs.
  - Having more regular reviews of their condition
  - Providing more information about their condition and the possible impact of their condition on them over time
  - Providing extra support to cover the associated costs with being disabled
  - More frequent contact to check if the care and services they are receiving are still appropriate and relevant.
- **Training staff and improving disability awareness** - During the interviews the view was expressed during our interviews that health and social care professionals should have greater empathy and understanding about mobility and disability conditions and that co-production in service design including assessment processes, better training and wider education is key to addressing these issues.

It was emphasized that the training should be wider than a simple disability awareness course. It should be co-produced with disabled people. It should also be designed in such a way that commissioners and staff achieve a greater understanding of how to properly assess a person’s individual disability to ensure the best outcomes are achieved.

It is essential the skill set covers both social and health care within the assessment process, so that a holistic approach is taken regarding the needs of the disabled person and their families.

This approach would support the ambition set out in the Locality Plan “to create a more coherent, cohesive and integrated commissioning landscape, by bringing together the Health and Social Care commissioning functions of Bury Council and Bury CCG into One Commissioning Organisation, with a pooled or aligned budget, a single commissioning strategy, a shared approach to maximising social value, and strategically commissioning for outcomes”.

Our respondents said;

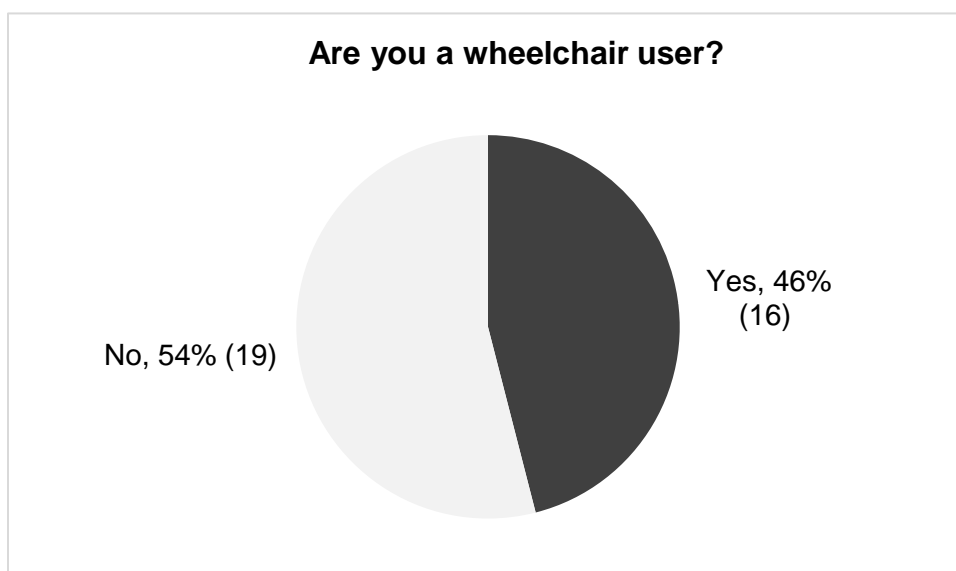
*“Somebody could contact me to see if I will benefit from any care”.*

*“More contact needed”*

*“Understand the person what they are going through. Their need for help”*

*“Having a social worker coming to me and discuss my disabilities.”*

#### 4.6 Wheelchair services



Just under half of our respondents were regular wheelchair users and they provided a mixed response regarding the wheelchair services.

- **Repairs** - Of those respondees who use wheelchairs, 31% (5 people) found wheelchair repairs service to be very responsive or had no concerns. However, for one person it had taken over 6 weeks to repair their wheelchair and the following week it broke again requiring a further 10 days to be repaired.

Healthwatch Bury has previously received concerns regarding the difficulty in getting the right type of wheelchair and the particular problems encountered with the service only being able to offer a standard model whilst theirs is being repaired.

- **Contacting the service** - 50% (8) found the service hard to reach by telephone and found the waiting times too long.

- **Lack of Enough Wheel Chair Friendly Ambulances** - We were also made aware of an issue for wheelchair users who may require an emergency ambulance. Currently not all the makes of ambulances used by NWAS are able to transport the different types of wheel chair. So if the ambulance cannot take the wheel chair with the disabled person their wheelchair then has to be taken to them via a family member or friend which may not always be possible.

Our responses mirror the national statistics<sup>9</sup> which show that around a fifth of disabled people report having difficulties related to their impairment or disability when accessing transport. The report also stated that 'transport is the biggest concern for disabled people in their local area. Pavement/road maintenance, access and frequency of public transport are the biggest issues', all of which were raised by our respondents.

- **Pavements** - A number of comments were made about the pavements not being mobility friendly.

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<sup>9</sup> The Disability in the UK 2016 facts and figures report

*“Pavement could be improved for such as myself using mobility scooters”*

*“The pavements are dangerous (flags raised)”*

*“Lack of dropped kerbs in my area...”*

#### **4.7 Other Comments - Access to Information**

Respondents also highlighted difficulties in accessing information about what is available in the borough. Many service users we spoke to do not feel comfortable accessing information via the internet and rely on getting information through ‘word of mouth’ from their friends or through their social worker.

Healthwatch Bury highlighted this issue in their comments on the draft Locality Plan earlier this year. We stated:

*“All plans of this nature will need to embrace new and emerging Information and Management Technologies but it is important to recognise the need to put service users’ needs first and to acknowledge that many may struggle with technology including but not limited to for example:*

- *over 3500 adults in Bury have learning disabilities and others with dyslexia which affects 10% of the population*
- *the older population - research has shown that 71% of 65-74 year olds use the internet but this falls to around 37% of people over age 75 years*
- *those with cognitive disabilities and cognitive decline, such as dementia, a growing problem in Bury and nationally*
- *individuals with low literacy - around 16% of adults in England are described as ‘functioning illiterate’ according to the National Literacy Trust.*

*It would be helpful to reference/recognise as part of the work going forward that digital services are designed with those and other needs in mind to ensure services and information technology platforms are accessible to all.”*

A consistent message being received by Healthwatch Bury, from both this research and our wider conversations, is that for our most vulnerable in society the internet is not a tool they like to use or would turn to for help, information or advice. It is, therefore, important that all health and social care services continue to provide and make available information through all communication channels.

## **5. Recommendations**

Healthwatch Bury recommend the following:

### **i. Personal Assistants**

- Provide greater levels of support, advice and guidance for disabled people in their roles as an employer and in finding the right PA's through for example, help with recruitment and HR advice.
- Co-develop a service users guide on rights at work for both the PA and employer.
- Further develop the local support available to help all disabled people.
- Include a specific section for promoting the work and roles of PA's in the Bury Directory to enable disabled people to advertise for positions and PA's to promote themselves.
- Help promote the role of a PA as a career through the development of a PA Network where PA's can find information, advice, toolkits, update their skills, access training opportunities including e-learning, job vacancies, share experiences and networking events.
- Enable salaries to match skill set and expertise required rather than tied into a set hourly rate.
- Empower disabled people by enabling greater flexibility of how they use their personal budgets to cater for social activities and other needs when required.
- Commission a pool of PA's to provide cover for sickness, holidays and training days. This could be developed as a GM initiative thereby helping to ensure work for the PA's employed via the pool.

## **ii. Transport**

- For Bury Council to work with other GM Councils and lead on developing a common policy on the licensing of taxis and private hire vehicles to ensure conformity, quality assurance and a consistent approach to the interpretation of recommendations made at a national level.
- Bury Council to take a more proactive approach to ensure a greater number of rear loading taxis/PHVs are available and of appropriate design to serve wheelchair users.

## **iii. Voluntary Sector**

- For the Council and CCG to work with the voluntary sector to develop a commissioning and funding framework that sets out the Council's commissioning and model for funding which aims to help the sector remain viable and fully able to play a significant role in supporting the needs of all disabled people across Bury.
- Commission and invest in local groups and organisations. Having access to local organisations providing a wide range of services, advice and advocacy support is vital in providing people with access to the services and funding they need and are entitled to. This is a priority for those for whom English is a second language. Such organisations, with their wealth of local knowledge and information, are better able to reflect local need, to inform the design of services, delivery of policies and procedures for the most vulnerable in Bury.

## **iv. Assessments & Funding**

- Record and or film assessments so that any challenges, to what was said or agreed by both sides can be more easily reviewed. This would also have a significant benefit on cost and time as any appeal process would be more straightforward.
- Build on the opportunities available through Devo Manchester and the coming together of the Local Authority and NHS commissioners to review and streamline



all assessments procedures and policies to ensure a more holistic and joined up approach to the services and funding available.

- Bring together health and social care assessments and budgets to reduce bureaucracy and duplication.
- Apply a 'tell it only once approach' to assessments so that service users only have to explain their needs and situation once.

**v. Health and Social Care**

- Develop with service users a staff training and awareness package
- Ensure co-production in service design, including all assessment processes, training and wider education on disability.
- Review the adaptation service to assess and identify opportunities to simplify and streamline the processes and reduce waiting times.
- Support the development of an annual event where commissioners, service users, local service providers and disability groups can come together to discuss issues, share ideas and show case good practice.
- Review the policy and contract specification for ambulances, to ensure any new vehicles are able to accommodate all types of wheelchairs.

- vi. **Improve access to information** - Continue the development and promotion of services and information through all communication channels. A hard copy of all community groups would be a helpful asset to the residents of Bury.

**6. Conclusion**

Healthwatch Bury would like to thank all those who contributed to this report. It is clear that there are many challenges facing all disabled people not just those with mobility issues. By taking more time to listen and co-produce policies and services with service users will help ensure services meet the needs of the most vulnerable in our society.

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**Bury CAB Case Studies – PIP**

*Client part of a family with employed partner and dependent children. She was on DLA care and high rate mobility. She was assessed for Personal Independence Payment (PIP) and awarded enhanced rate daily living and standard rate of mobility for an ability to walk 20-50 m. She can walk 10 metres and after needs a wheelchair. The appellant has no use of her left hand side following severe illness and has fits. The HCP reports she can walk to a local landmark. This is 1/3 mile away and appears to be an error. This was pointed out the department but who still upheld the decision to award standard rate mobility and not the enhanced which is an ability to walk 0-20 metres. Appeal pending.*

*Single male severe vision impairment, has uncontrolled Type 1 Diabetes, severe kidney stones, degenerative disk disease, and depression. He was found fit for work. He was interviewed in bed on a home visit by CAB staff due to pain and poor mobility. When out he needed a wheelchair that needed to be pushed at Tribunal. He had evidence from his GP that confirmed severe disablement. Case was upheld by department to Tribunal. The Tribunal quickly placed him in the Support Group and apologised to him.*

*Client suffers COPD Arthritis Cardiovascular disease and is diabetic. Client was awarded standard rate PIP Mobility for an ability to walk up to 50 metres with repeated regularity in a reasonable time. She reports that she had to stop within 20 metres and was on oxygen 16 hours a day and had a portable bottle when walking. Client won PIP enhanced mobility rate at appeal.*

*Single Claimant male is wheel chair bound. The ESA assessment awarded 0 points on the grounds he can manually propel his wheel chair 200 metres with repeated regularly. He was found fit for work. This is the legal criteria. The appellant agrees*

*he can manually propel his wheel chair over 200 metres. He won his appeal but on grounds of mental health. The Tribunal agreed 0 points for the mobilising descriptor because he could manually propel his wheel chair 200 metres repeated regualy. Mobilising under ESA does not just look at walking.*

*Client suffers from severe back and hip pain due to a below knee amputation, arthritis in shoulders and hands causing numbness, diabetes's, locked fingers, shortness of breath and depression. He was awarded 0 points in a recent ESA assessment and declared fit for work. He had a previous ESA appeal that also awarded 0 points in 2013. This was appealed at that time and he was awarded 30 points for physical difficulty. He was also awarded PIP enhanced rate mobility at the same period as the latest ESA decision. Appeal pending.*

*Client has severe coronary artery disease, two dropped feet, no sensitivity in both feet, knees do not lock and very poor balance. He received DLA high rate mobility and was transferred to PIP. In the application form he stated he could walk 50 metres but would stop many times and was very unsteady. He used two crutches and leg braces. This would arguably be the criteria for DLA High Rate Mobility which was replaced for him after an assessment with the standard rate of PIP mobility for difficulty walking between 20-50 metres. He appealed and won the enhanced rate of PIP mobility. This highlights the tightening of the physical mobility criteria from DLA to PIP.*