## **Your Support Matters**

# Before and Beyond Covid: The Effects On PA's and IE's In Greater Manchester

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### **Table of Contents**

About This Report	2
Key Messages	3
Chapter 1: Introduction	4
1.1 Report Aims	4
1.2 Report Methods	5
1.3 Report Structure	5
1.4 Survey Demographics	6
1.5 Report Objectives	8
Chapter2: Background and Context	9
2.1 Adult and Social Care Statistics in Greater Manchester	9
2.2 Validity of the information on the Local Authority websites	10
2.3 Role of Personal Assistants	11
2.4 Inequalities in Greater Manchester	12
Chapter 3: Before Covid	13
3.1 Before Covid: Results	15
Chapter 4: During Covid	20
4.1 During Covid: Results	23
Chapter 5: Beyond Covid	28
5.1 Beyond Covid: Results	30
Chapter 6: Conclusions	34
Recommendations	35
Chapter 7: Appendices	36
Bibliography	37

## **Acknowledgements**

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We would also like to thank the Winston Churchill Memorial Trust for selecting us to carry out the research as part of the COVID-19 Action Fund 2020 and for supporting our vision to improve adult social care across Greater Manchester. Their support for our ideas has been unwavering.

## **ABOUT THIS REPORT**

Your Support Matters have been commissioned to undertake this research by the Winston Churchill Memorial Trust (which William Case is a lifelong fellow of) as part of the COVID-19 Action Fund which Your Support Matters successfully applied for in May 2020.

Part of the commission was to look at the ways PA's and Individual Employers could be better supported throughout Greater Manchester.

The Action Fund helped us set up an emergency COVID-19 phone line for Personal Assistants (PA's) and Individual Employers (IE's) which generated several queries relating to confusing information, poor advice and isolation.

Worrying trends were emerging during our conversations with people, with most feeling ignored, excluded and fearful due to scare mongering from the mainstream media, as well as on social media.

This was compounded by boroughs and Local Authorities being under prepared for COVID, and how to support the most vulnerable people across Greater Manchester. This led to our desire to not only support PA's and IE's during this time, but also undertake research to change this.

This isn't political activism but rather using our knowledge, passion and experience to influence and improve decision making around social care policy for the benefit of disabled people and their families, as well as for front-line workers in adult social care.

We'd like to add that this report isn't just for PA's, but rather we hope it will appeal and resonate with people who are support workers, care workers and unpaid carers too.

## **KEY MESSAGES**

The following policies should be implemented for the wellbeing of PA's and Individual Employers across the Greater Manchester to improve their working conditions:

- There needs to be a standardised introduction for PA's and Individual Employers before the employment/agreement is signed.
- This training should be delivered by recognised training providers in Greater Manchester and VSE/CIC organisations such as Your Support Matters. These include (but are not limited to) 'How to Be a Good Employer' course and 'Roles and responsibilities of being a PA' course.
- There needs to be an introduction of PPE training for PA's and Individual Employers prior to employment and regular training throughout their time and this should be updated regularly. The regular training should be accredited which could count towards further or higher education if they wanted to.
- Standardised hourly pay across Greater Manchester for PA's. This should be in line with national pay, in line with a living wage and not the minimum wage.
- A co-ordinated ID scheme for PA's to be recognised as Key Workers and include them in a Key Worker scheme set up and directed by Greater Manchester Health and Social Care Partnership.
- The GM wide PA and IE network forum to be set up by the GMHSC for the purposes
  of supporting and helping PA's across Greater Manchester. This should opportunities
  to network, raise issues and buddy-up schemes. This could be delivered borough wide
  as well as regionally too.
- o Introduce a GM wide mentor/buddy scheme for PA's so that new PA's are supported during their first 4 months of employment.
- Include PA's into the NHS Blue Card Discount Scheme whilst PA's are supporting IE's in Greater Manchester and would be two cards in one; it would be an ID card as well as a discount card.
- Social workers should be updated, trained on the social model of disability. The training should be provided by people who have lived experience and who live in the borough of the Local Authority such as a DPO (disabled person's organisation) or CIC.
- Local Authorities should move away from care agencies and use direct payments and the PA system.

## 1.INTRODUCTION

The effects of the pandemic will be felt for many years to come. The strain and demands on the NHS and in adult social care have been well documented for over a decade. The way it is funded (and underfunded) continues to divide party politics and the pandemic exposed how grossly underfunded it has been. On top of this, the pandemic exposed how reliant we are on care workers and how poorly paid they are.

The media often used the term "underlying health conditions" when documenting the number of deaths of disabled people from COVID-19, as if it was inevitable that anyone with disabilities or with certain conditions would die. The callousness and insensitivity of the term shocked the disabled community.

When 1.2 million people were asked to shield, disabled people accepted this as the norm because they have always felt isolated, socially excluded, and have lacked resources to get through their ordinary day. These problems were not the result of COVID-19 rather, this has always been their reality.

### 1.1 Report Aims

The report aims to highlight the poor working conditions of PA's and the difficulties faced by Individual Employers, for the purposes of influencing Local Authorities and CCG's to change and adapt the way they deal with the disabled people in Greater Manchester.

Our model of approach is based on first-hand experience of disabled people who have over 30 years of knowledge of personal budgets, as well as using approaches such as community wealth building and the social model of disability.

This means that Local Authorities and CCG's, as well as the Greater Manchester Health and Social Partnership, have a pivotal role in promoting the social model of disability, as well aligning their policies to moving more disabled people on to direct payments.

Each borough should be encouraged to follow this method of approach rather than the disconnected policies that currently exist across Greater Manchester. Currently every borough has different criteria for receiving a direct payment and this report will demonstrate that this causes problems that could otherwise be avoided.

### 1.2 Report Methods

#### These included:

- Quantitative research including surveys and national statistical reporting
- Qualitative research including interviews with Individual Employers, Personal Assistants.
- Desk-based analysis of reports, presentations over zoom
- Webinar based research from policy makers from Social Care Futures, Kings College London etc.
- o Up to date media resources.

### 1.3 Report Structure

Part 2 *Background and Context* analyses the demographics of the disabled community who responded to our report as well as looking more closely at PA's, their role and the basic historical background to personal budgets.

Part 3 *Before Covid* looks at the differences in approach and policy across the Greater Manchester region and the effects that this has had on PA's as well as the stress on Individual Employers *prior to the pandemic* which we have previously researched. <sup>1</sup>

Part 4 *During Covid* then looks at the effects of the pandemic on PA's and Individual Employers including and looking at the survey more closely from those who were ignored and felt isolated and the worrying trends. This is then backed up by wider reports from Skills for Care and Kings College London.

Part 5 *Beyond Covid* is where we look at some of the suggestions made from our interviews and questionnaires as well as identifying two boroughs that have major policy flaws and where they and other boroughs and Local Commissioning Groups could improve.

Part 6 *Conclusions and Recommendations* offers the opportunity for real change to improve processes for PA's and IE's across Greater Manchester.

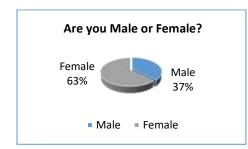
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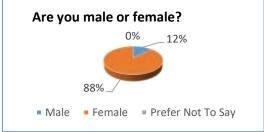
<sup>&</sup>lt;sup>1</sup> Your Support Matters, Fair Pay for PA's in Bury, 2019

### 1.4 Survey Demographics

The number of people who responded to the survey and who were interviewed was disappointingly low. Overall, we only reached 40 people (20 PA's and 20 Individual Employers) and this means that the survey is by no means representative of how all PA's and IE's feel.

In total, 88% of PA's who answered our survey were women with slightly fewer women being Individual Employers at 63%.





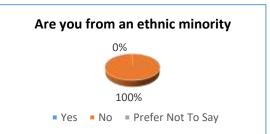
Individual Employer Survey – 2020

PA Survey – September 2020

This fits in with more recent studies from Skills for Care who discovered that the majority of women are working as care assistants or support workers.<sup>2</sup>

In terms of ethnic minority, 100% of those who responded to our survey said that they weren't from a ethnic minority.





Individual Employer Survey – 2020

PA Survey – September 2020

We know that by looking at the data provided by Skills for Care, around 4% of the care work/support work force are from non-EU countries and 9% of the total adult social care work force across the North West. <sup>3</sup>

The lack of response from the ethnic minority background is a reflection on us rather than the work force. We recognise that a generic online questionnaire is not enough to engage with people so going forward, we will engage with community centres, faith groups and disability organisations (DPO's), to improve our policy suggestions and ensure that they are leading and guiding our work. It was difficult to do this during the pandemic.

<sup>&</sup>lt;sup>2</sup> Skills for Care, State of the Adult Social Care Workforce, 2020

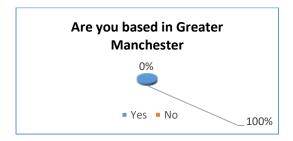
<sup>&</sup>lt;sup>3</sup> Skills for Cate, State of the Adult Social Care Workforce, 2020

### There are some possible explanations for the poor response:

- PA's didn't have time to engage with surveys. They just wanted to get on with the doing the job.
- IE's were probably self-isolating and didn't want to engage with research like this.
   Possibly the timing wasn't right.
- Suspicion that if Individuals Employers comment about the issues they're facing or criticise the system that they will have their support withdrawn. There is a lot of fear amongst the disabled community which we documented in our report in 2019. <sup>4</sup>

Attendance at our PA forum was poor during the pandemic even though it was held on Zoom, which suggests to us that PA's didn't want to engage with anything other than the job they were employed to do. Morale was low, times were difficult and a forum was the last thing they wanted to think about.

Since we are looking specifically at Greater Manchester, we thought it was appropriate for us to find out whether PA's were having to travel throughout the region.



PA Survey – September 2020

It was necessary to ask this question because the distance that PA's have to travel to a shift was identified as one of the main contributors to their stress, as well as for the PA/IE relationship breaking down.

Also, it shows whether there are enough PA's being employed within the borough they live in, which can improve the working conditions of PA's because they are familiar with the area.

<sup>&</sup>lt;sup>4</sup> Your Support Matters, Fair Pay for PA's in Bury, May 2019

### 1.5 Report Objectives

### This report aims to:

- o Highlight some of the issues that PA's and IE's faced before the pandemic.
- The impact of the pandemic on PA's an IE's rights
- Suggest a way forward for Greater Manchester Health and Social Care Partnership (GMHSC), Department of Health and Local Authorities to improve the situation for PA's and IE's.
- Provide a practical way forward at regional level for Greater Manchester policy makers to improve the working conditions for PA's throughout the region.

## 2.BACKGROUND AND CONTEXT

#### 2.1 Adult Social Care Statistics in Greater Manchester

Since 2016, Greater Manchester has had a devolved Adult and Social Care budget of over £6 billion. The Greater Manchester Health and Social Care Partnership (GMHSC) was established to oversee the spend and to improve the lives of 2 million people who live across Greater Manchester.<sup>5</sup>

The GMHSC oversees the wellbeing by localising care and ensuring that each borough is in control of how they can deliver services, so that it is tailored to the people in each borough. Their holistic approach covers everything from pollution to obesity, reducing drug and alcohol dependency across the region. But whilst this seems to be a great idea, in practice devolution isn't working and has serious flaws.

Freedom of Information requests obtained from Local Authorities across Greater Manchester show that there are over currently 1396 disabled people in receipt of a direct payment, of which 823 are employing personal assistants<sup>6</sup> with Rochdale having the largest number of Individual Employers.<sup>7</sup>

This is in stark contrast to the number of people who are employing carers or care workers via approved agencies. There are approximately 220,000 people in the North West receiving adult social care services (either residential, home care or via direct payments)<sup>8</sup> and these numbers don't include unpaid carers such as friends and family.

The statistics reveal a worrying trend across the region, showing that when the disabled people are approved a package of support the Local Authorities immediately default to approving care agencies to help them. This perpetuates the myth that disabled people need to be cared for.

It undermines the Care Act, which was introduced to empower disabled people to choose the type of support they wanted, as it placed responsibility on Local Authorities to ensure that social workers are following the guidelines to encourage choice.

From our FOI requests, Salford has one of the lowest numbers of disabled people on direct payments or on in receipt of a Personal Health Budgets (PHB) in the whole of Greater Manchester. As a Local Authority they are over reliant on outsourcing work to care agencies.

Councils see it as being easier to employ a care agency worker rather than a PA and fail to understand that care agencies cost more in the long run, because they don't meet all the requirements of the disabled person, often know little about the area and don't personalise the support for them.

<sup>&</sup>lt;sup>5</sup> Greater Manchester Health and Social Care Partnership, 2016

<sup>&</sup>lt;sup>6</sup> See appendix, FOI Requests, page 36

<sup>&</sup>lt;sup>7</sup> See appendix, FOI Requests, page 36

<sup>&</sup>lt;sup>8</sup> Skills for Care, The Adult Social Care Workforce in the North West, 2020

A fifteen-minute visit will never be adequate or acceptable for someone who is sick, let alone who is disabled and it's not acceptable for carers to not to turn up for a shift.

Given that Greater Manchester has a devolved health and social care budget and the GMHSC holds policy making powers for the region's health, we wonder whether they regularly monitor the number of health budgets and direct payments and are monitoring the numbers of PA's.

The reason we ask this is because there should be a database of the numbers held centrally in the region and so that the GMHSC can report to individual Local Authorities so that they can encourage them to increase their PA numbers by implementing new policies.

### 2.2 Validity of Information on LA Websites

Local Authority websites were generally poor when communicating the role of personal assistants, personal budgets and the choice available to potential individual employers.

For instance, Tameside MBC had easy to access information as it was clear, precise and detailed the different stages of accessing a budget and assessment. Stockport MBC and Trafford websites were similar in some ways, as they were easy to follow and clear but some of the information on Stockport Council's website was misleading. For example, they state that if a person goes into hospital on a long-term basis the individual cannot access a personal budget, but this policy changed nationally at the end of 2019.

On the other end of the scale, Bury's website was incredibly disappointing since there was no information about direct payments and only mentions supported living and leans more to the older people in the borough who need support.

As we know there is a common misconception that all disabled people are old or children and it is wrong for any Local Authority to perpetuate those myths. On the whole, Bury's website doesn't provide all the information on the various options of support that are on offer across the borough.

The same goes for Salford MBC where there is literally no information about personal budgets, direct payments, or personal budgets. It provides no information on the support available to people with disabilities, or for the families of people with disabilities.

If Greater Manchester is meant to have a devolved health and social care budget then you would think there would be a standardised information from one borough to the next. Instead, what people are faced with is a post code lottery as to the type of support and the options available to them. For those people who are most in need living in poorer areas will more than likely, end up in care homes.

This is a sign that the adult social care services are at the mercy of Local Government budgets and this attests to the questionable cost effectiveness of Local Authority policies that are dependent and reliant on outsourcing their services. It also suggests to us that adult social care services are being directed by people who don't know what independence is and see

disabled people as only having a right to exist rather than live, which is why they only want to direct people to the preferred way of being supported.

There are noticeable exceptions including Wigan and Tameside who have proved that their adult social care services can be transformed to support people and give them choice as to how they wish to be helped.

#### 2.3 Role of PA's

The recent push from the GMHSC to fill seven hundred PA roles across the borough by holding care shows. This proves to us that decision makers still don't know what a PA does <sup>9</sup>. PA's aren't carers and Individual Employers never consider themselves as being 'cared for' or part of the care industry.

Language is important. Being cared for suggests that the person has no right or choice over their life and is entirely dependent on the system, where as a PA empowers IE to make the decisions for themselves and enable them to live the life they want to.

## "18,000 [PA's] were carrying out 23,000 jobs in 2019/20". 10

Because of the growing size of the PA workforce and their invaluable role in an individual's life, they are represented in various ways such as PA Framework meetings with Skills for Care, PA meetings with the Greater Manchester Health and Social Care Partnership (GMHSC) and more recently via the PA Forum in Bury set up by Your Support Matters.

Yet despite their growing representation, a PA's role is often misunderstood and misrepresented, or sometimes left out of literature by the Department of Health. This contributes to the low morale that is felt by PA's across the region, one that was felt before the pandemic.

However, we do acknowledge that there are PA roles to fill and a possible suggestion for promoting these roles could be to put greater emphasis on the quality of the job provided to the Individual Employer. Quality is never compromised because a PA doesn't have to rush to fulfil other shifts, there are no fifteen-minute visits, rather the PA is consistently with the same person for the majority of the time.

Being a PA isn't like any other role in adult social care. It is unique because it is guided by the individual rather than the agency and, because each individual is unique. No two people are the same.

<sup>&</sup>lt;sup>9</sup> Greater Manchester Health and Social Care Partnership, https://www.gmhsc.org.uk/news/appeal-to-fill-700-personal-assistant-in-care-vacancies-across-greater-manchester

<sup>&</sup>lt;sup>10</sup> Skills for Care, The Adult Social Care Workforce Report, 2020

### 2.4 Inequalities in Greater Manchester

It's worth noting that seven out of ten boroughs in Greater Manchester are below the national average when it comes to poverty, jobs and opportunity. <sup>11</sup> This means that as a region, Greater Manchester is failing the expectations of those who are vulnerable because, there are more people who could be considered vulnerable, living in the region. As outlined in the Marmot review, disabled people are more likely to unemployed or more likely to lose their job. <sup>12</sup>

A couple of examples of this are that disabled people are more likely to have their contract stopped before their probationary period has ended or are more likely to be made redundant or offered voluntary redundancy.

One of the areas of worry was the low income and high unemployment levels across the region as well as the low pay. Research carried out by Skills for Care in 2020, found that there were over 9,000 empty positions for PA's, with over 36,000 jobs being zero-hour contracts in adult social care. <sup>13</sup>

One of the main issues facing the adult social care workforce is the perception that support workers and care worker are low skilled, poorly paid and undervalued.

Unless you're a doctor or a nurse many roles within adult social care are often looked down upon and this is certainly the case for the role of a PA and yet, we haven't even touched on unpaid carers who often fill in when care workers fail to attend a shift for instance.

<sup>&</sup>lt;sup>11</sup> Professor Marmot, Health Equity in England; Marmot Review 10 Years on, February 2020

<sup>&</sup>lt;sup>12</sup> Professor Marmot, Health Equity in England; Marmot Review 10 Years on, February 2020

<sup>&</sup>lt;sup>13</sup> Skills for Care – PA Workforce Report, 2018 to 2019

## 3 BEFORE COVID

Ten years of Conservative austerity has had serious consequences on the quality of care provided by local authorities and the NHS. It has meant the criminally under-funding of adult social care since 2010, at a time when demand for adult social care services has increased but the Local Minimum Grant has decreased. This has meant many people being left without support in the community and in some cases, councils being unable to provide a direct payment or personal health budget 15

Outsourcing and commercialisation have seen the wealth extracted from the local economy and health providers and instead, passed on to agencies that are only interested in making a profit. <sup>16</sup> Care providers are extractive in nature since Local Authorities are effectively outsourcing care services to outside commercial organisations.

One reason is for this, is that Local Authorities are familiar with the process. It is quick and easier to implement rather than recruiting a PA which is more time consuming. One could say that domiciliary care workers/ care work model fit the traditional view of disability and of disabled people. They are vulnerable so therefore need to be cared for, rather than supported and encouraged to make their own decisions instead of being told what to do.

There is a disparity of hourly pay rates for PA's across Greater Manchester. As Your Support Matters reported in 2019, PA's can expect to be paid different rates of pay for the same job, leaving many PA's stressed and feeling under valued and Individual Employers living in fear that their PA will leave them for a better hourly rate in another borough. <sup>17</sup>

Before COVID, there was the lack of acknowledgement and recognition of a PA's role in the community. Whilst assisting an Individual Employer to their doctor appointments, doctors fail to know acknowledge them and believe that they are just another person that the patient knows. There is no formal recognition of their profession or their role within adult social care.<sup>18</sup>

This is important because it causes stress for the IE as well as the PA, who must continuously explain what the role of their PA is. This comes back to the idea that carers are easier to identify than a PA. They are the only unregulated group of workers in adult social care, despite the fact that they provide a 1-2-1 care and personal or medical support on a daily basis and there is little, or no training required to be a PA. <sup>19</sup>

Another possible reason for this, is that so few disabled people have PA's and there is a reluctance for Personal Assistants to be employed. This comes back to a disabled person being denied the right to choose what support they receive. Social workers are not trained in the

<sup>&</sup>lt;sup>14</sup> George Stye, How do social care funding cuts affect the NHS?, The Health Foundation, 2018

<sup>&</sup>lt;sup>15</sup> Kings Fund, Social Care Services; Funding Cuts Are Biting Hard, January 2020

<sup>&</sup>lt;sup>16</sup> CLES Report, A progressive approach to adult social care, 2020

<sup>&</sup>lt;sup>17</sup> Your Support Matters, Fair Pay for PA's In Bury, 2019

<sup>&</sup>lt;sup>18</sup> Gill Manthorpe, Under the Radar; GP's Experiences of Direct Employees for Older People, August 2019

<sup>&</sup>lt;sup>19</sup> John Woolham et al, The Impact of Covid on People who work as PA's, Kings College London, July 2020

social model of disability which in our view, is the reason for their lack of understanding and progressive views on disability.

The Social Model frames disability as something that is socially constructed and that impairment is, and always will be, present in every known society and that the only logical position to take is plan and organise society in a way that includes rather than excludes disabled people. <sup>20</sup>

Your Support Matters have given guest lectures at Manchester Metropolitan University (MMU) on the social model and was one of the main suggestions in our report into fair pay for PA's. <sup>21</sup> This is on-going and has been designed by people who have lived experience of disability.

Without knowledge of the social model, social workers cannot offer the proper support that a person requires, to enable them to live their life rather than merely existing. Disabled people aren't able to fulfil their potential due to the lack of support offered by Local Authorities.

Disabled people are often criminally overlooked in the workplace and in the community and this affects their wellbeing and health. Being stuck at home waiting for carer workers to arrive for short visits doesn't allow a disabled person to fulfil their potential. A PA enables a disabled person to live a varied life, to contribute to their community and use their skills and talents. A system that prevents that is a system that's not worth tweaking but overhauling completely.

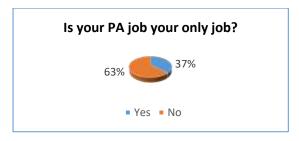
PA's have never been considered important and their voices have often been ignored and their job deemed to be unimportant or insignificant. Long before COVID, there has been systematic problems that have existed to contribute to disabled people feeling invisible and isolated.

<sup>&</sup>lt;sup>20</sup> Barbara Lisicki, Inclusion in London, 2013

<sup>&</sup>lt;sup>21</sup> Your Support Matters, Fair Pay for PA's in Bury, 2019

## 3.1 BEFORE COVID: RESULTS

Before the pandemic PA's weren't expected to be trained and Individual Employers weren't expected to provide an induction. This wasn't an initial concern for PA's until it became an issue midway through a contract of employment. <sup>22</sup> These factors perpetuated the idea that a career in adult social care was for the unskilled, low paid and a stop gap until something better comes along. <sup>23</sup>



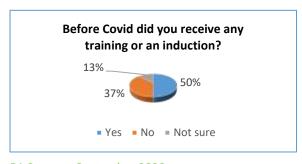
PA Survey - September 2020

37% pf respondents said that the role of a PA was merely a stopgap to another career and expressed frustration at the lack of professional fulfilment. <sup>24</sup> As one respondent told us she felt disillusioned with the role and the lack of respect she had received as a PA.

## "A job at ALDI is considered more worthwhile than a job as a PA. No one knows what we do". Person E

Part of any job or career is to have continual training and development so that skills are refreshed but also that the workforce can feel confident that they are doing their job properly. In most occupations it is usual to receive an induction or training, especially when the person has never worked in the sector before.

Therefore, it is concerning to find that the less than half of the PA work force we surveyed had never received an induction or training throughout their contract of employment.



PA Survey – September 2020

It suggests that the role of the PA is quite straightforward and that anyone can do it, when the reality couldn't be more different, especially when PA's provide 1-2-1 support to people with dementia and conditions such as cerebral palsy.

<sup>&</sup>lt;sup>22</sup> Skills For Care Report, 2015

<sup>&</sup>lt;sup>23</sup> Slills for Care and Your Support Matters, Fair Pay for PA's 2019

<sup>&</sup>lt;sup>24</sup> Skills for Care report, 2016

Another issue was that PA's felt left out of the decision-making processes at local and regional level. In our previous report published in 2019, not one PA said that they had never met a representative from their LA or been invited to attend any meetings relating to their job as a PA role. They felt as though they were undervalued and ignored from the process and this contributed to poor working conditions.

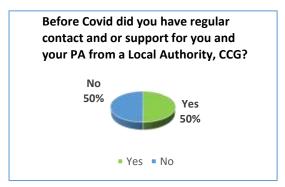
With this in mind, over 88% of PA's said that they had received no support from the LA, CCG or other agency (including the brokerage service that was dealing with their contract). A brokerage is an integral part of personalisation as they assist with PA recruitment, payments and contracts as well as providing support to PA's and Individual Employers.



PA Survey - September 2020

And it wasn't only PA's that felt this way, Individual Employers felt ignored too.

50% of the people we surveyed said that they had received no help, guidance or support from their LA or CCG.

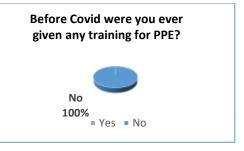


Individual Employer Survey – September 2020

The reason we consider this to be important is because during the pandemic, journalists and local politicians thought that certain problems were purely unique to the pandemic. However, people have been experiencing this *before* the pandemic. So, the stories of there being no coordination of services and people feeling left in the dark were not just symptomatic of the Covid.

There was more demand on Personal Protective Equipment (PPE), the costs of which are usually funded by the Local Authority or the Individual Employers. PPE isn't just masks but includes sheets, aprons and shoe coverings depending on the individual needs. Every PA and IE should be trained to use them to ensure that health and safety guidelines are followed. Therefore, it is worrying that not one PA or IE who answered our survey had ever received any PPE training from their CCG or LA.





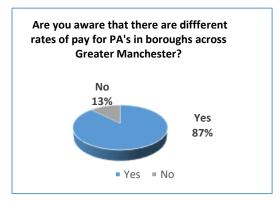
PA survey – September 2020

Individual Employer Survey – September 2020

It is also worth adding that the payment of Personal Protection Equipment (PPE) is dependent on whether the LA has the funds to cover it and whether it is within in their remit to pay for it. Some Local Authorities do whereas others don't such as Bury and we find this perplexing and concerning.

Since Greater Manchester has a devolved health budget you would think that there would be standardisation of rules and policies relating to a person's package of support, but the reality is, it isn't.

An individual Employer in Trafford could receive assistance for their PPE but if they moved to Bury, they would have to purchase it themselves. It's a post code lottery which leaves some people able to access appropriate support and other left behind. This is not just frustrating, but also creates divisions and resentments between disabled people and their families.

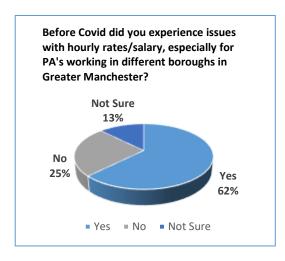


The most contentious issue before Covid-19 amongst PA's and for Individual Employers was their fears that their PA's would leave them for a better rate of pay somewhere else during our PA report in 2019. <sup>25</sup>

IE Survey - September 2020

Two years on, there appears to have been no major improvements across boroughs in Greater Manchester.

<sup>&</sup>lt;sup>25</sup> Your Support Matters, Fair Pay For PA's in Bury, 2019



For Bury however, we acknowledge that some attempt has been made to uprate Individual Employers to £9 per hour and one of the brokerages quoted back many of our recommendations and proposals back to us, so the message is reaching, albeit slowly.

IE Survey – September 2020

During one of our interviews with an individual employer they disclosed that their local authority actively pressurised them into accepting a care agency, not just because it saved time to do so but because of the cost of recruiting a PA.

"Salford decided for me that I should have a care agency. They were against the idea of PA and I had no choice but to accept their decision".

Person D, September 2020

As we have already stated, the Care Act is there to encourage choice, enable self-advocacy and ensure that the disabled person has the right to choose the support they wish to have. In some cases, people can have a combined package which includes a care agency and a PA, or a full time PA. The idea that disabled people should just 'accept their lot' and be grateful for whatever scraps of assistance they can get is in breach of the Care Act and the standards it's meant to uphold.

"I've been living with my conditions all my life, I know what's best for me and yet I'm being denied what is best for me. These problems were around long before COVID-19 even existed". Person D, September 2020

Some of the issues that 'D' faced when she attempted to apply for a direct payment included continuous delays to the process by social workers, being told that she was not able to make right or logical decisions, as well as being told that a direct payment would take too long to set up.

Her testimony isn't unique. Unfortunately, throughout our research we uncovered historical breaches of the Care Act and more often than not it was because disabled people were told that they couldn't have a PA or, that the situation would be easier for Local Authority to manage if a care agency was involved.

## **4 DURING COVID**

# "Covid-19 is not the great leveller. Some people will be more affected than others". Emily Maitilis $^{26}$

Anyone who was vulnerable before the pandemic was left out to dry by a system that was already against them, but the pandemic became an opportunity to make the system even more punitive and cruel with the implementation of the Coronavirus Act, which makes for alarming reading.

Enacted by the Health Secretary, Matt Hancock on the 25<sup>th</sup> March, The Coronavirus Act was a way of implementing emergency powers across the country during lockdown. For instance, in the Local Authority Care and Support; Part 1; Powers and Duties of Local Authorities in England states that:

"A Local Authority does not have to comply with any duties imposed by the following provisions –

Section a of the CA 2014 (care act) which are the assessment of an adult's needs for care and support, section 10 of that act (assessment of a carer's needs for support) and –

Section 12 of the act (duties to give written records of assessments)" 27

The Local Authority have the power to use their discretion rather than their duty to follow the Care Act. The Local Authority can enact these powers at any time they feel necessary, which means they only have to provide basic provision for their communities, rather than ensuring that the most vulnerable are properly supported.

In some cases, Local Authorities were changing packages of support without informing the individual or family and in some cases, this affected the hours of support that they were able to pay for their PA's or other representatives.

As it states in the Coronavirus Act 2020, the Social Workers Act of 2018 can be overridden or subject to modifications in the case of employing emergency temporary social workers:

<sup>&</sup>lt;sup>26</sup> BBC Newsnight, 2020

<sup>&</sup>lt;sup>27</sup> Cornovirus Bill, March 2020

**"12ATemporary registration in emergencies involving loss of human life or human illness etc** 

(1)The regulator may register a person as a social worker, or the persons comprising a specified group of persons as social workers

(2)For the purposes of paragraph (1)(b) the emergency registration requirement is met—

(a) if the regulator considers that the person is a fit, proper and suitably experienced person to be registered as a social worker with regard to the emergency.<sup>28</sup>

There is no robust checking of the social workers credentials. At no stage should a pandemic be an excuse to breach the Care Act or open the system up to mistakes being made on a regular basis, especially when some people have debilitating and potentially life limiting conditions.

But as Dr Janet Hoskin and Dr Jo Finch state, the social care system has been using terms such as "underlying health condition" for many years, as though it was no surprise to anyone that a disabled person would die. <sup>29</sup>

"The idea that poverty and isolation or even early death is somehow natural and normal for disabled people and it's worryingly prevalent". 30 Dr Frances Ryan

Furthermore, some social workers have been particularly vocal about the obvious disabling policy outlined in the Coronavirus Act because there is an obvious dumbing down of legislation and these easements threaten the duty of care of Local Authorities. <sup>31</sup>

The act sets a dangerous precedence, as it openly undermines the social care regulations that exist to protect people in Local Authority care who are undergoing assessments and who require emergency intervention.

The Coronavirus Bill makes society question who is valuable and worth saving in our society.<sup>32</sup> Every social work policy must be questioned now, given that they have clearly failed so many people in society.

Over one million Do Not Resuscitate (DNR) letters were sent out to the most disabled and elderly in society, which proved that the pandemic was being used a form of indirect discrimination towards disabled people, especially those with learning difficulties.

<sup>&</sup>lt;sup>28</sup> Covid Act 2020, https://www.legislation.gov.uk/ukpga/2020/7/schedule/5/enacted

<sup>&</sup>lt;sup>29</sup> Dr J Hoskin and Dr J Finch, Covid 19; Disability and the new Eugenics, Social Work 2020

<sup>&</sup>lt;sup>30</sup>Dr Frances Ryan, What Kind of Society Have We Become?, Guardian, June 2019

<sup>&</sup>lt;sup>31</sup> Dr J Hoskin and Dr J Finch, Covid 19; Disability and the new Eugenics, Social Work 2020

<sup>&</sup>lt;sup>32</sup> Dr J Hoskin and Dr J Finch, Covid 19; Disability and the new Eugenics, Social Work 2020

Yet, there was some glimmer of hope because for the first-time technology such as zoom, as well as options to work more flexibly have been embraced more than ever. You could say that the pandemic proved the social model of disability works<sup>33</sup>.

## "Flexibility and support were offered during the pandemic so why not before?" <sup>34</sup> Dr Frances Ryan.

Disability campaigners have worked tirelessly to make workplaces more inclusive but were often overlooked, because the proposals were deemed unworkable or a strain on services and workplaces. It seems that only when non-disabled people were affected that flexible working was taken seriously.

<sup>&</sup>lt;sup>33</sup> Narray Doyle, Mad In America, Forbes Magazine, May 2020

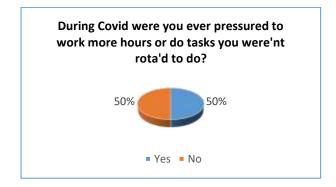
<sup>&</sup>lt;sup>34</sup> Dr Frances Ryan, Mad in America, Forbes Magazine, May 2020

## 4.1 DURING COVID: RESULTS

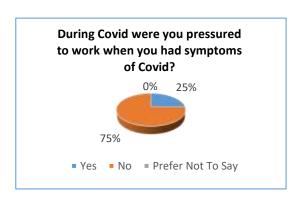
"The low paid will be the ones expected to carry on even when they're ill which can't be right or acceptable". <sup>35</sup> Andy Burnham, Mayor of Greater Manchester.

For those people who were working on the front line, there was no avoiding the unique challenges of the pandemic. We saw increase demands on supermarket staff, delivery drivers, post people who helped keep the country going. But for many of these workers, they had to work even when they were sick.

Low paid workers couldn't afford to be furloughed or to take time off due to Covid symptoms, and of some of these front-line workers included PA's.

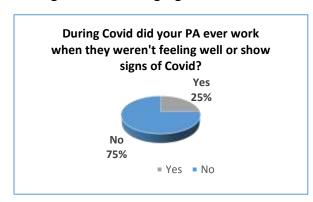


PA Survey – Before and Beyond Covid – 2020



PA Survey – Before and Beyond Covid – 2020

PA's said they felt guilty that they were letting their Individual Employer down if they were feeling sick or showing signs of Covid.



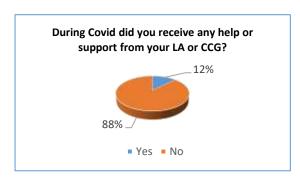
IE results – Before and Beyond COVID report – 2020

IE's felt they had no choice but to do this because there was no other support available to them. Their families were isolating and shielding and some IE's stated that they didn't have any other support network. LA's didn't offer to assist them, neither did the brokerages.

Page | 23

<sup>35</sup> BBC Newsnight, 2020

This showed a trend amongst the respondents that they were isolated and alone which caused stress, confusion, and high levels of anxiety amongst the respondents. Both IE's and PA's felt the same way.



PA's expressed disillusionment with the system during a time of stress and felt they had no one to talk to or go to for guidance, particularly around areas such as PPE and payments.

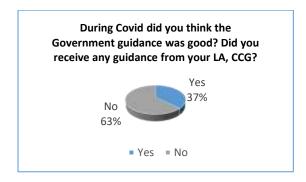
PA Survey – Before and Beyond Covid –2020

It was during the pandemic that Your Support Matters set up an advice line for PA's and IE's but this was only set up in June 2020. Imagine if the GMHSC had provided such a service? They could've report trends to Local Authorities and monitor PA recruitment and the number of IE's across the region, and support PA's regionally.

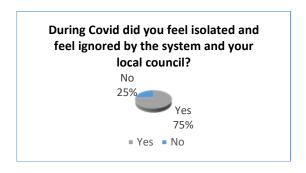
Similarly, IE's said that they received no guidance or support from the LA's, which coupled with the poor guidance from the Government, left them feeling confused and isolated.

"I felt that social services should have been ringing round those vulnerable to check they were okay, I only found out about a few things from by business PA".

Person A, September 2020



IE Survey – Before and Beyond Covid – Sept 2020



IE Survey – September 2020

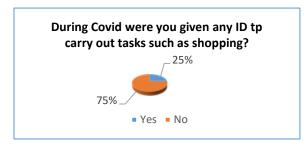
These results also back up the report carried out during the pandemic by the Greater Manchester Disabled People's Panel (GMDPP) which stated that many disabled people experienced confusing messages from the Government, a lack of support and that many of

them felt they were digitally excluded and didn't know about the community hubs that existed throughout the region. <sup>36</sup>

Community Hubs can support people when it comes to collecting medications, shopping, and general support to ensure that our most vulnerable (whether young or old) are supported. The existence of community hubs was obviously not marketed or promoted well, because so many people who responded to our survey were not aware them. There was no joined up thinking and knowledge between the LA's, CCG's and regional decision makers such as the GMHSC and the GMCA.

Some services across Greater Manchester were rolled back. Adult social care departments never returned calls and social workers were difficult to contact. Time and time again, Your Support Matters received complaints from PA's and IE's that Local Authorities were delivering a poor service or only contacting people in extreme circumstances.

"My levels of isolation became so extreme that there had to be special agreements to allow me to have extra support as I began to lose time". Person X, October 2020



PA Survey – September 2020

PA's expressed dismay at the fact that they experienced difficulty in getting ID to collect medication and to use at supermarkets.

PA's had to struggle because they weren't recognised as key workers. For us this is shameful and proves that they are, on the hole, forgotten about by various authorities across Greater Manchester. This situation could've been avoided. The Department of Health could've issued a letter along with LA's, CCG's, Skills for Care and the GMHSC.

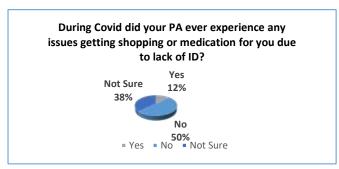
A question worth asking is, what is the point of a devolved health and social care budget when there are inconsistencies across the region? When there are inconsistencies in service? When some boroughs support PA's and others don't, you have to question the effectiveness of decision makers.

Some Local Authorities were forward thinking though. Following our FOI requests from Tameside, Trafford and Rochdale, each of them ensured that PA's had a letter to take with them to the supermarkets, pharmacies and other essential places, but not all LA's did this.

<sup>&</sup>lt;sup>36</sup> GMDPP, GM Big Disability Survey: Covid 19, August 2020

Many IE's who responded to our survey stated that their PA rarely disclosed any issues with them, which is why only 38% of employers said that they were unsure if their PA had trouble while they were out.

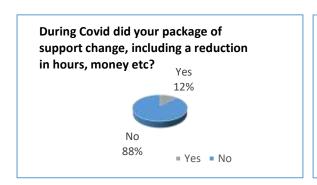
## "Just get on with the job and battle through each day. Each day did seem like a battle, a war and it was tiring". Person J



As discussed in chapter 3, PA's were generally excluded from the traditional forms of support to the point that even GP's didn't know what they did. Is it any surprise to find that PA's were forgotten about during the pandemic?

Individual Employer Survey – September 2020

Neither Skills for Care or the Kings College Fund asked Individual Employers whether their support packages changed during the pandemic, so Your Support Matters found that it was an area that required some researching, especially since the COVID-19 Act had been introduced and allowing Local Authorities to enact emergency powers and not follow the established guidelines.



If you answered 'yes' to the previous question, were you given any warning that your package was going to change?

No Yes 50%

Yes 50%

Individual Employer Survey - September 2020

Individual Employer Survey – September 2020

We know that these results are by no means representative of the IE experiences during the pandemic, but we still found it alarming that two people found their package of support change without prior consultation. One person based in Wigan disclosed to us that because her PA left during the pandemic but the council never informed her that they had employed a care agency to take over the package of support. There was no consultation, and she was given no choice or say in the matter.

"One day I had support and the next day I was informed that my hours had been reduced. I became stressed and had no idea of what to do".

Person B, September 2020

This is worrying for several reasons.

- o There is no time to plan or put in a contingency plan to support the individual
- o The Induvial Employer becomes stressed and anxious
- The PA might leave

Their experience was by no means unique, as one person divulged to us that Salford City Council decided to cut her hours midway through the pandemic when infection rates were increasing, to the point where it was impossible to recruit a PA. She was therefore forced to accept a care agency which she didn't want.

"No one would want to work for 7 hours a week anyway, but I felt that they were making it harder and harder for me to get the support I wanted. I realised that this was a cost cutting exercise".

Person D, October 2020

The Covid-19 Bill is a way of rolling back support and therefore the role that the state and Local Authorities responsibilities to those we need to support in times of need. The fact that due process can be so easily breached and overlooked is not only worrying but sets a dangerous precedence.

## 5 BEYOND COVID

The Kings College Fund research in 2020 was one of the most comprehensive studies into the experiences of PA's that has been conducted, but failed to offer any meaningful suggestions for a potential way forward. Consequently, Your Support Matters wanted to find out what regional PA's and Individual Employers wanted to see change.

CLES (Centre for Local Economic Strategies) has offered some suggestions that align with the ethos of Your Support Matters. Local Authorities should use the knowledge of regional DPO's and CIC's who have the knowledge and expertise at ground level to influence policy and know how best to provide services to the vulnerable and disabled people. <sup>37</sup>

There are some well-known examples of how the community wealth building model has helped to transform boroughs, for example, the Preston Model is one shining example of a council that was bankrupt and had one of the highest levels of deprivation in the country, to being able to provide high quality services and support to the people who needed it the most.

Wigan's 'The Deal' has had a similar affect; Community Interest Groups (CIC's) and Disabled People Organisations (DPO's) have been at the heart of providing good quality support to people at a time when austerity had hit the council hard, but mistakes continued as highlighted in the previous chapter.

Looking ahead, there must be a new way for boroughs across Greater Manchester to deliver the services and support to disabled people. It's simply bewildering to us that PA's are still facing the same problems that they have been for years.

Councils still think it's acceptable for disabled people to accept what they're given, rather than create a package of support that is tailored to the requirements of the individual. We can't reiterate it enough that it costs more for a Local Authority to source a care agency in the long run, than it does for them to recruit a PA for a disabled person.

In recent months we have heard various politicians use terms such as 'Build Back Better' and 'Bring Back Better'. Everyone from President Joe Biden to the Greater Manchester Mayor, Andy Burnham, have been used as rallying cries for demanding change and never to return to the way things were done before the pandemic.

But we can't help but feel that much of this is just an empty promise. Services are at the mercy of Government funding and there are attitudinal and ingrained problems across the system that will take much more than slogans and half-hearted measures to rectify.

There are also the effects of long-covid and the impact that this will have on public services including access to support in the home, housing etc and they could potentially become a higher priority over those who have sick or disabled before Covid-19.

Page | 28

 $<sup>^{37}</sup>$  CLES, A progressive approach to Adult social care, page 6 to 7, 2020

### Who will be prioritised?

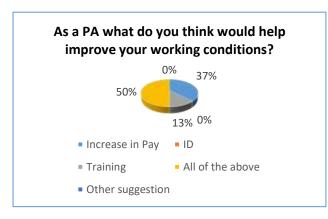
The speedy response from the Government to help prioritise those people diagnosed with long Covid, proves that all the help is available when it affects recently disabled people, whereas the majority of the disabled people have had to fight and struggle for assistance.

A recent example of this is when disabled people have had to claim the new style ESA (Employment and Support Allowance) via the DWP. The notification from them says that people with Covid are being prioritised and anyone without it will need to wait 5 weeks before their claim is looked at or assessed.

The responses given here from our surveys and interviews are insightful and offer some opportunity for small gains forward for PA's and Individual Employers across the region, which would, to some degree, improve the working conditions for PA's.

### 5.1 BEYOND COVID: RESULTS

Throughout the report we have highlighted how tough working conditions have been for PA's, so when they were given the opportunity to express what changes they would like to see, they were passionate about receiving training and an increase in pay.



PA Survey - September 2020

Given that PA's throughout Greater
Manchester are paid at different rates,
this makes it especially important that pay
rates are standardised. A package of
measures that are interlinked to enable
PA's to carry out their duties-hassle free is
also required. For instance, collecting
prescriptions, accompanying the IE to Dr
and hospital appointments etc without
having to explain what they do.

They have to be recognised by all of the services including housing, NHS and social services and there has to be communication between all of these services to make it easier and more efficient. An IE shouldn't have to constantly explain that they have a PA.

As can be seen from the above, the package includes ID, training at the start of their employment and during it, as well as an increase in pay.



Individual Employers also felt that they required training in self-advocacy and employment law (for employing a PA) including sickness and day for instance.

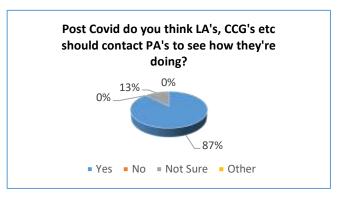
Individual Employer Survey – September 2020

As one person stated in the responses, it is important to diffuse difficult situations and training would have been especially helpful during a difficult time.

Other Individual Employers said that training would've been useful for negotiating their own support plans with social workers. During one interview with an Individual Employer, they stated that on many occasions they were made to feel like they were over emotional, not

assertive enough, and not knowledgeable enough about the process or even about their disability.

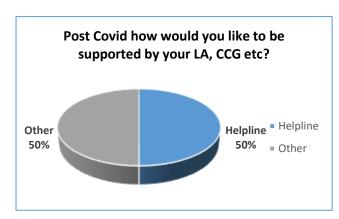
## "I wanted to feel like I am in control of my own support. I know what is best for me." Person N



One of the biggest issues that PA's and IE's expressed was the lack of contact from their LA and/or their CCG. This comes down to, two simple things; LA's recognising that the PA are carrying out an important role in the community and that they are often working on their own without the support of an agency or other company for support.

PA Survey – September 2020

## "We feel we're out there on our own, trying to cope with little guidance or assistance". Person L



Individual Employer Survey – September 2020

For individual Employers, they suggested that a helpline for PA's and IE's would be helpful either at borough level or at regional level. Incidentally, Your Support Matters set up a hotline midway through the pandemic to help assist and answer any queries from furloughing staff to PPE. Although the call numbers were quite low the fact that people knew we were there gave IE's and PA's some peace of mind.

"Once the social worker and the LA approve of your package, you never speak to them again unless they want to reassess you".

#### Person N

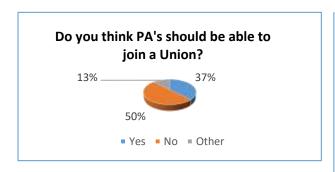
One suggestion that has been discussed by researchers in disability and Personal Assistance is the idea of PA's becoming unionised or setting up a Co-operative alliance to increase representation.

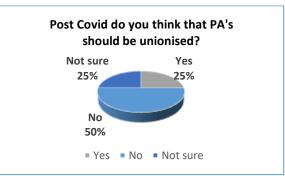
UNISON formerly included PA's into their bargaining powers in 2010 but some of their proposals are unworkable. For instance, standardising all training when in reality it's not possible to do this because each Individual Employer will have their own requirements, and the job is bespoke to the person receiving the support.

Both Individual Employers and PA's we surveyed were split about the idea of unionising PA's.

# "I don't want to do anything that will complicate or potentially undermine the relationship I have with my Individual Employer".

Person M, 2020





PA Survey, September 2020

IE survey, September 2020

However, representation matters to both PA's and IE's and they liked the idea of borough wide forums or regional ones too.



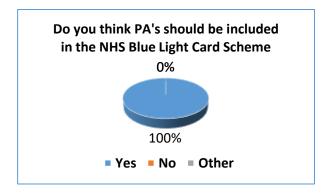
Before lockdown, Your Support Matters set up a forum in Bury to represent PA's and IE's and was well attended. During the pandemic, we conducted the meetings over zoom which had a lukewarm response, but IE's still felt they were necessary and important. Just because there was a low attendance doesn't mean that they weren't needed or required.

IE survey - September 2020

Stress and low morale were the obvious reasons why PA's didn't want to attend the forum. It was a good idea but at the wrong time, but also we have to accept that everyone at the time was coping with the situation the best way they could. PA's wanted to get on with the job and battle through because they knew they had to.

A way forward could be that each LA or a CCG could facilitate a forum for PA's and IE's as a safe space to raise issues locally and this is a good opportunity to connect with borough wide decision makers which Your Support Matters suggested in 2019. <sup>38</sup>

But the overwhelming agreement between PA's and IE's was to introduce or include PA's into the NHS Bluecard scheme, which offers discounts for PA's when in restaurants etc. On the surface this may seem like tokenism but for PA's, it is important that they are included in the same schemes as carers and other NHS workers. It is a small gesture of honouring the good work that they do for disabled people in the community.





PA Survey, September 2020

**IE Survey, September 2020** 

Although these are merely suggestions for helping to improve the working conditions for PA's and IE's on the ground, they would help to ensure that the PA's are considered just as important as other key workers. A PA seems to be treated like a different employee despite working in people's homes and providing care and support. <sup>39</sup>

<sup>&</sup>lt;sup>38</sup> Your Support Matters, Fair Pay for PA's in Bury, 2019

<sup>&</sup>lt;sup>39</sup> Kings College London, The impact of covid on people who work as social care personal assistants, July 2020

## **6 CONCLUSIONS**

The adult social care system was already broken before the pandemic. Low pay, under representation and lack of choice were issues that disabled people have been campaigning against for a long time and were not unique to the time we were living in.

The dependency of Local Authorities and more specifically social workers to employ care agencies has proven to be a failure, not least because they're on the whole, expensive and don't fulfil all of the duties set out in the care plan to a high standard.

There is a lack of quality, care and attention paid to those who require support in the community. This model doesn't work in the long run, because friends and family intervene to fill in the gaps that the care workers are unable to perform. Communities fail because of the over reliance on care agencies and care workers.

Personalisation of care is important for disabled people and with it, PA's and Individual Employers should be fully supported in the role so that this unique partnership can flourish. Disabled people are worth more than a fleeting 15-minute visit every so often. They have a right to live a full life and PA's enable them to do that.

If Greater Manchester is to prove that a devolved budget can work, then there has to be standardisation of policies and social work processes across the region. There needs to be an end to the post code lottery, to ensure that all disabled people are guaranteed a fair chance to control their choice of support.

## **Recommendations**

The following policies should be implemented for the wellbeing of PA's and Individual Employers across the Greater Manchester to improve their working conditions:

- There needs to be a standardised introduction for PA's and Individual Employers before the employment/agreement is signed.
- This training should be delivered by recognised training providers in Greater Manchester and VSE/CIC organisations such as Your Support Matters. These include (but are not limited to) 'How to Be a Good Employer' course and 'Roles and responsibilities of being a PA' course.
- There needs to be an introduction of PPE training for PA's and Individual Employers prior to employment and regular training throughout their time and this should be updated regularly. The regular training should be accredited which could count towards further or higher education if they wanted to.
- Standardised hourly pay across Greater Manchester for PA's. This should be in line with national pay, in line with a living wage and not the minimum wage.
- A co-ordinated ID scheme for PA's to be recognised as Key Workers and include them in a Key Worker scheme set up and directed by Greater Manchester Health and Social Care Partnership.
- The GM wide PA and IE network forum to be set up by the GMHSC for the purposes of supporting and helping PA's across Greater Manchester. This should opportunities to network, raise issues and buddy-up schemes. This could be delivered borough wide as well as regionally too.
- Introduce a GM wide mentor/buddy scheme for PA's so that new PA's are supported during their first 4 months of employment.
- Include PA's into the NHS Blue Card Discount Scheme whilst PA's are supporting IE's in Greater Manchester and would be two cards in one; it would be an ID card as well as a discount card.
- Social workers should be updated, trained on the social model of disability. The training should be provided by people who have lived experience and who live in the borough of the Local Authority such as a DPO (disabled person's organisation) or CIC.
- Local Authorities should move away from care agencies and use direct payments and the PA system.

## 7. APPENDIX

### **FOI REQUESTS FROM LA'S 2020**

<b>Local Authority</b>	<b>Number of PA's</b>	<b>Number of Direct</b>	Date of FOI
		<b>Payments</b>	
Bolton	DNA	1236	2 <sup>nd</sup> September 2020
Bury	312	587	27 <sup>th</sup> September 2020
Manchester CC	DNA	622	8 <sup>th</sup> September 2020
Oldham	746	1039	16 <sup>th</sup> October 2020
Rochdale	428	739	21st September 2020
Salford	52	65	12 <sup>th</sup> October 2020
Stockport	128	1068	16 <sup>th</sup> October 2020
Trafford	206	487	20 <sup>th</sup> August 2020
Tameside	189	270	8 <sup>th</sup> September 2020
Wigan	759	1107	7 <sup>th</sup> September 2020

Code: DNA = Did Not Answer

FOI = Freedom Of Information Request

### ABBREVIATIONS USED THROUGHOUT THE REPORT

PA = Personal Assistant

IE = Individual Employer

CCG = Commissioning Group

LA = Local Authority

GMHSC = Greater Manchester Health and Social Care

GMCA = Greater Manchester Combined Authority

DP = Direct Payment

PHB = Personal Health Budget

FOI = Freedom of Information Request

GMCDP = Greater Manchester Coalition for Disabled People

### **OUR MAILING LIST FOR SURVEY AND INTERVIEWS**

Communic8te Bury Bury Health Watch

PIP Professionals Greater Manchester Disabled People's

Panel

Future Directions CIC Pathways Associates

GM Gold Bury VCFA

Early Break Greater Together Manchester

Breakthrough Bury Involvement Group in Mental Health

People's Care Agency Manchester Community Central

People's History Museum

**Greater Manchester Coalition for Disabled People** 

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