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UK COVID-19 INQUIRY
MODULE 6

WITNESS STATEMENT OF BANANE NAFEH ON BEHALF OF DISABILITY RIGHTS UK

I, Banane Nafeh, will say as follows: -

1. I make this statement in relation to the impact of the COVID-19 pandemic. This statement is made in response to a Rule 9 request for evidence for Module 6 of the COVID-19 Public Inquiry which is examining the impact of the COVID-19 pandemic on the publicly and privately funded adult social care sector and those providing unpaid adult social care. I make this statement on the basis of my own knowledge or belief. Where something is outside my own knowledge, I refer to the source.

My background

2. I live in a flat in London with my husband and young daughter. In September 2020 my elderly parents also moved in with us. They did so after the death of my older sister with whom they used to live. I will speak about this later in this statement. My parents have only very recently moved out.

3. I have had muscular dystrophy since birth and also have a heart condition. I am a wheelchair user. Due to my progressive muscular dystrophy, I need support with personal care, meal preparation, and domestic tasks such as cleaning and shopping. These are the tasks that either my family members, or my PAs, assist me with.

4. I have a care package in the form of a personal budget 'Direct Payment' equating to 25 hours per week of PA support. I employ my own PAs to support me every day. I usually employ four regular PAs, but I also have an additional PA who I can call upon in an emergency. During the pandemic I was lucky enough to have additional support from my family although many others did not have this support and so relied entirely on their PAs.

5. I do not use care agencies and rely only on PAs. There are some differences between PAs and carers that I believe meant those who used PAs could be in a better position during the pandemic than those who relied on care agency staff.

    5.1. Firstly, carers employed by a care agency change frequently resulting in no consistency in social contact. Where social contact was limited during the pandemic, building a close bond with a small group of PAs would have been beneficial to Disabled people who were otherwise socially isolated. I found this beneficial myself.

    5.2. Secondly, carers employed by an agency generally spend less time with the person they are caring for than a PA. This meant that in the pandemic, those with a PA would have had more time to engage in conversation and enjoy much needed human contact than those who received care from care agency staff. There was a time when I only needed 4 hours' a week care. I would find my carers would come and work for much less than that time, in a rush, so they could get the job done as quickly as possible and move on. Personally, I have had a much greater degree of warmth and trust with PAs and it feels much more like a collaborative relationship.

5.3. Finally, PAs generally work with one person and my PAs only work for me (except for my emergency PA who works for more than one person on an emergency basis). Care agency staff on the other hand would move from one setting to another which in the pandemic would have increased the risk of virus transmission.

6. Regarding employment, I work as a Personal Budget Advisor on the Disability Rights UK ('DR UK') 'Personal Budget Helpline' and have undertaken this role for almost 16 years. The Helpline is a telephone and email service that provides advice to individuals and organisations on personal budgets, Direct Payments, accessing social care funding, care needs assessments, employing PAs and non-residential community care charges. We do not advise on social security benefits, equipment/aids and discrimination related issues. The Helpline service also offers advice on managing self-operated care packages (such as opening a separate bank account and keeping a record of how the budget is spent), including general advice to potential users of Direct Payments and self-funders on the responsibilities and legal requirements involved in employing staff/PAs who support Disabled adult social care users in everyday life.

7. Part of my job involves explaining what personal budgets are, how people can be in control of their care packages and that they can use the payment flexibly in accordance with the legal framework and the Care and Support Statutory Guidance. I also advise on whether a spouse, or a family member that lives in the same household as the person they support can be employed as a PA, as this is permissible in exceptional circumstances. I also advise on the consequences of the individual's Care Support Plan and Action Plan, for example, the breakdown of their budget and how it is to be spent including the amount to be paid to PAs in wages, holiday pay, sick pay, parental leave as well as payroll services, contingency planning, insurance policies and HMRC

and NI contributions. I would also advise on what amounts to 'disability related expenditure' for the purposes of a financial assessment of an individual's contribution to the cost of their care and support

8. Overall, the DR UK Helpline faced a huge increase in calls during the pandemic because of the confusion callers faced; it was one of the busiest times that I have known on the Helpline in the nearly 16 years since I have been working there. The key themes I remember included difficulties in accessing PPE, confusion as to how Direct Payments could be used, and how to challenge the reduction in the "socialising element" of their payments. The socialising element of a care package refers to support provided to help people engage in social activities and avoid isolation, and I talk more about this below.

9. Some people were worried about what would happen if there were an accumulation of Direct Payment funds which were unspent for reasons associated with the pandemic. In addition, there was confusion as to whether PAs were included in the list of 'key workers' who could continue to work. PAs themselves were asking us whether they were permitted to continue to work, fearing arrest if they left the home for this purpose. Other Disabled people called us, confused as to how their PAs could visit them with reduced public transport available and whether they could use Direct Payments to pay for taxis or other 'ride hailing' apps for their PAs. I will address some of these issues later in this statement.

10. In this statement I will draw on my own experiences, those of my direct family and also my knowledge of the issues raised with the DR UK Helpline by adult social care users.

Some positives

11. With regard to the impact of the pandemic upon me and Disabled adult social care users more generally, I should start with the positives. Firstly, I was able to spend a great deal more time with my young daughter which meant that the

family bond within our home became stronger as I'm sure it did for many other people during the pandemic.

12. Secondly, there were also some benefits introduced during the height of the pandemic such as home working which helped many Disabled people including those who receive adult social care and have the support of PAs. Although I was able to work at home just as much as I needed to before the pandemic, I am aware the move to home working benefited many Disabled adult social care users.

13. Thirdly, during the pandemic there was greater recognition by Local Authorities of the flexibility in how Disabled people could use Direct Payments. Although securing that recognition took time and was inconsistent across the country, where it was recognised, it was a considerable benefit.

14. As an advisor on the DR UK helpline in the pandemic, I would often advise Disabled people that they could use their Direct Payments flexibly in a way that best supported them and their changing needs. For example, Chapter 1.1 of the Care and Support Statutory Guidance says: *"1.1 The core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life. Throughout this guidance document, the different chapters set out how a local authority should go about performing its care and support responsibilities. Underpinning all of these individual 'care and support functions' (that is, any process, activity or broader responsibility that the local authority performs) is the need to ensure that doing so focuses on the needs and goals of the person concerned."*

15. Also, Chapter 12.35 of the Guidance says: *"The direct payment is designed to be used flexibly and innovatively and there should be no unreasonable restriction placed on the use of the payment, as long as it is being used to meet eligible care and support needs."* This is under the heading of *"paying family members"* but applies more generally to the Direct Payment Scheme. On the

advice line I would rely upon these paragraphs, and the Guidance more generally, to support Disabled people in identifying how they could use Direct Payments in innovative ways to meet their own specific needs.

16. For example, during the pandemic and having taken a detailed account of a person's full range of needs and outcomes, I advised some callers they could use their Direct Payments to purchase digital devices such as smart phones or laptops to facilitate their communication with the outside world during periods of lockdown and/or shielding, to help counter and address the social isolation that was otherwise being suffered.

17. I am aware that Local Authorities accepted, in response to individuals requesting it, that Direct Payments could be used to purchase digital devices such as tablets and laptops. I know these devices were a vital lifeline to aid social contact for those who were otherwise isolated. This was a way in which the 'socialising element' of their care package could be spent when other opportunities for social contact were not possible.

18. Another example would be that a Direct Payment could be used to pay a neighbour or friend to cook meals for somebody who could not cook for themselves in circumstances where their PA could not attend either. That might be because of reductions in services which forced a reduction in PA hours, or because that PA had left the role, or because they could not attend having contracted Covid-19.

19. Some local instructions suggested the payment could not be used to purchase PPE where a Local Authority was supposed to be providing it. However, even where the Local Authority was supposed to be providing it, PPE was not always available. Therefore, there were circumstances where the Direct Payment could be used to buy PPE.

20. All of these innovative and flexible uses of Direct Payments were possible, and as an experienced advisor I was aware they could be lawful in certain

circumstances. They could greatly enhance a Disabled person's quality of life in lockdown and their personal safety and help them to adapt to the emergency situation. Where applied, they illustrated the benefits of Direct Payments over and above Local Authority directed care. However, these benefits were not consistently realised across all Local Authorities.

Difficulties in using Direct Payments during the pandemic

21. There were several difficulties Disabled adult social care users who called the advice line faced. Firstly, one difficulty especially in the earlier part of the pandemic, was that Disabled people who wanted to secure agreement from a Local Authority to use their Direct Payment in a new way, often found it difficult to get through to anyone there who could authorise it in advance. There was a great deal of fear and anxiety on the part of Disabled adult social care users that if they did use their Direct Payment in new ways the funds could be recouped by the Local Authority later, placing them in debt, or even stopped altogether. This might happen if the Local Authority decided after the fact that they did not agree with the use of the Direct Payment.

22. Based on DR UK advice, a person might take steps to spend their Direct Payment in a different way than what had previously been agreed, but in a way that was nonetheless necessary on the basis of their changing circumstances. Some Local Authorities would then question, verbally, the person's new use of their funds. The Disabled person would tell the social worker that they had been advised by DR UK that their new use of a Direct Payment was permissible. They would come back to me for advice. I would suggest they ask the social worker to put in writing the legal basis upon which the payment could not be used in such a manner. In all those cases about which I am aware, once a social worker had been asked to put their objection in writing, they did not do so, and there was no further challenge or recoupment of funds. I cannot recall any example of a challenge to my advice being maintained by any Local Authority during the pandemic but the initial indication that there would be a

dispute nevertheless caused a great deal of anxiety to Disabled adult social care users.

23. Secondly, I am aware from my work on the advice line that there was inconsistency as to how Local Authorities across the country were supporting Direct Payment recipients and a lack of clarity in how Direct Payments could permissibly be used. It took too long for relevant guidance to be produced with the first guidance issued on 21 April 2020. The initial guidance was not sufficiently clear, did not respond to people's concerns and was subject to changes over time. For a user of adult social care at home who relies on daily support, this would have been a significant delay.

24. Thirdly, Local Authority social workers were often not able to answer questions as to whether Direct Payments could be used in a necessary, but innovative way to meet an adult's needs.

25. I was understandably in a different position to many of the people who called me for advice given my years of experience in this area. I ensured my own PAs could come to my home to assist me and agreed that I would pay for their taxi fares through my own Direct Payments.

26. Another issue I received calls about on the DR UK Helpline during the pandemic was where a person in receipt of a Direct Payment had been hospitalised with Covid-19 and then, because they had been in hospital for more than 28 days, they had seen their Direct Payment terminated altogether. It was then incredibly difficult for them to get it reinstated after being discharged including because they could not get through to anyone at the Local Authority to review the decision. This led to people's essential needs not being met and considerable hardship. In cases where funding was no longer available for meal preparation it would lead to malnutrition. A lack of funding for personal hygiene needs would lead to people having to sit in their own urine or faeces

without support. I heard examples of these types of real-life stories as well as many more.

Access to Personal Assistants

27. I was lucky in that the number of PAs who supported me during the height of the pandemic only reduced during times when one of them was ill. When that happened, my family stepped in to help me. However, I am aware from my work on the advice line that there was a general reduction in the number of PAs during the pandemic. Some of them would have assisted people with leaving their homes and going to health appointments, shopping or family activities. Because of social distancing, those hours of work were no longer needed and many PAs found that they were unable to make ends meet with the reduced number of hours that would be made available to them. They therefore left their roles as PAs altogether and family members or others had to step in, where they were available. Access to PAs was in my experience especially problematic in rural areas.

Reduction in community services and support

28. At the height of the pandemic, I received numerous calls on the DR UK Helpline from Disabled adult social care users about the reduction in community services and support in their local areas. There has been a shortage of respite places in some Local Authorities for some time (even before the pandemic) with people accessing only bare minimum levels and often only after fighting to access them. The situation became even worse from 2020 onwards as respite and day services were closed all over the country. Respite services provide an essential break for Disabled people as well as for their care workers and unpaid carers; a real lifeline. There were cases of Disabled people calling the DR UK helpline extremely upset and concerned because they had nowhere to go. The extra time that Disabled people were forced to remain at home placed extra responsibility on carers who were looking after them which took a great toll on

their health and wellbeing. It also affected the quality of life of the person being cared for.

29. I saw a big reduction in community support across the country. As well as day services and respite centres, libraries are also often a big source of support for Disabled people but many of these were closed during the pandemic. In my local area day and respite services and libraries reopened more gradually than other places such as restaurants and pubs, and with restricted hours. They are now back fully operating in my area but it took a considerable amount of time for that to happen. I am aware that a number of day and respite services across the country remain closed.

30. Many adult social care users called the advice line to complain that the "socialising element" in their care packages had been removed because day services or centres were closed, or they were not permitted to go out for other reasons. As I explained earlier in this statement, the socialising element of a care package refers to support provided to help people engage in social activities and avoid isolation. This might include accompaniment to community groups or events (e.g. lunch clubs, faith groups, exercise classes), one-to-one companionship or befriending services or transport assistance to get to social venues.

31. In many cases, people were having the socialising element of their care packages removed without any assessment having taken place, based simply on the assumption that because the service they had previously accessed was unavailable, the Disabled person would not need any socialising element anymore. There should have been an assessment of what a person's eligible needs were in the changed circumstances of the pandemic, including their needs in relation to maintaining personal relationships and accessing facilities or services in the local community. There should have been consideration of how those needs could be met in alternative ways, before deciding whether a reduction in support was really justified.

32. For example, I know of some cases where a person who really needed companionship, for example because of their mental ill health and suicidal ideation, would use the socialising element of their care package to pay for extra hours' support from a PA just to spend some more time with them in their home. Previously these people had used the socialising element of their care package for attending day centres.

33. Once the socialising part of a care package was taken away there was often a considerable delay in reinstating it or it was not reinstated at all. It seems to me that the pandemic was being used as an excuse by Local Authorities to make savings to social care payments without having gone through necessary assessments and based on assumptions.

<u>Care needs assessments</u>

34. As I explained above, changes to people's care packages were often being made without assessments being carried out. However, where care needs assessments were taking place, they were generally happening over the phone or on-line in a way that was not capable of being done sufficiently well for a number of reasons. For example, as a result of their impairment, some people would find it harder to articulate their needs over the phone. Some people would rely on lip-reading if they had a hearing impairment. Others found that the telephone assessments were much shorter than their in-person assessments used to be.

35. In my own case, and in accordance with the Care and Support Statutory Guidance, I am supposed to have an annual review of my care needs assessment, but this was delayed for several months during the pandemic. My last review before the pandemic happened around December 2019. I did not have another review until May 2021. This is even though my own Local Authority did not invoke easements to the Care Act. I called to find out when

my review would take place and all I was told, when I could eventually get through, was that it would be "when social workers become available".

36. A timely review was important in my case not because my care needs had changed but because I needed to increase the amount paid to my PAs by inflation and to address the increase in the national minimum wage (which increased on 1 April 2020 and 1 April 2021). When my review eventually took place, these uplifts were authorised but in the intervening period my PAs would not be paid what they should have been if they stayed for as long as they were needed so I would let them leave early.

37. Although I did not require any increase in my Direct Payment to address any increase in my own care needs, I sympathise with people who did have increasing care needs during the pandemic but did not receive any increased Direct Payment when they should have done simply due to a delayed annual review. This led to people's needs not being met. For example, some might have become incontinent but not had their care plan updated to reflect this and so were forced to remain in soiled clothing. Others whose health deteriorated due to lack of exercise and muscle wastage might have required the use of a hoist but were not provided with this, or sufficient funding to employ the two PAs necessary to operate it. Others might have become slower in their movements around their homes but their care packages would not have afforded their carer enough time to support them in this.

38. I remember receiving DR UK Helpline calls from two Disabled people in the pandemic who said they could not get through to their social workers to arrange a care needs assessment and this had resulted in them not being able to pay the national minimum wage to their PAs. This resulted in them having to reduce the amount of time they had for PA support as they had to pay the national minimum wage.

39. In addition to the delay in the annual review of my care package, I experienced a great deal of difficulty in getting hold of anyone from social services over the

phone during the pandemic for other reasons. There were several occasions when this happened including when I needed to access PPE from the Local Authority but could not get through and another time when I needed to confirm whether my Direct Payments would still be received regularly despite pandemic related Local Authority staff absences.

Non-residential community care charges

40. One issue Disabled people have faced generally, not limited to the pandemic, is an inaccurate financial assessment of the non-residential community charge, which is what they have to pay towards the cost of their support. This can happen, for example, if there has not been a proper assessment of their disability related expenditure, their use of non-residential community care resources or their ability to pay. It results in people being left with very little income to survive and subsequent hardship.

41. In the pandemic, this problem was compounded by the reduced availability of Local Authority financial assessors who could otherwise carry out assessments and help Disabled adult social care users to challenge the amount they had to pay. This meant many people were being overcharged in the pandemic or were unable to afford the charges they were being asked to pay from their own income whether by way of wages, capital or benefits. Some people were still charged for services they could not use, for example for the use of day centres. In those circumstances Disabled people would be left without enough money for other essentials.

Access to healthcare

42. During the pandemic I suffered a significant reduction in access to healthcare, especially in-person healthcare. I found it impossible to secure a GP appointment in the very early days of the pandemic. At the outset, my GP had told me they could not see anybody in person and did not know how they would

operate. I was asked to call back in a few weeks by which stage they managed to set up an online booking system, but I was no longer able to have in person appointments. Also, the on-line booking system would not have been useful for Disabled people who did not have digital skills or digital devices.

43. Given my own impairments it is very important for me to have regular face-to-face appointments. For example, I am a regular patient at a neurology and neurosurgery department of one hospital where they assess the strength of my muscles in both hands and legs to identify any deterioration. This could not be done properly over the phone, but a telephone appointment is all that they could offer me. I also go to another hospital where my lung capacity and breathing is checked, and I have associated CT scans and ultrasound scans but none of that happened during the pandemic. This caused me great anxiety that my health might have deteriorated without being monitored, or that I might have developed additional undiagnosed health needs. These anxieties are not fanciful; I have a progressive health condition which also increases the risk of me developing secondary health conditions. Finally, I had to endure many months of painful toothache until I saw dentists again maybe around 8 months after I needed to. My dentist explained that they could not see people even in an emergency during that time.

44. I am aware from my work on the advice line that I was not alone in facing substantial difficulties in accessing healthcare during the pandemic. I remember receiving calls from Disabled people who are adult social care users who complained that essential surgery had been rescheduled for many months and in one case remember this was for as long as two years. Although delayed surgeries affected many people in the pandemic, the burden of this for many Disabled people would have been particularly significant, exacerbating the pain and damage to their quality of life they already suffered because of pre-existing long-term conditions and inadequate care support.

Delayed occupational therapy support

45. Delayed occupational therapy support was a significant problem for me in the pandemic and I know it also affected many others. I have a heavily adapted bathroom where there is an Aerolet Toilet Lift which reduces the strain I otherwise experience when transitioning from my wheelchair to the toilet and vice versa. It also reduces the risk of falling and my reliance on carers which helps me maintain some independence. In addition, I have a special type of anti-slip flooring in the bathroom which aids my mobility reducing the risk that I will suffer an injury that could be caused on an otherwise wet and slippery bathroom floor.

46. Just before the pandemic, my flooring was damaged and in the first few months of the pandemic the toilet lift broke. It is the responsibility of the occupational therapy department within the Local Authority, following a referral by a social worker, to ensure these are assessed and repaired or serviced. Due to pandemic related delays, the likes of which I have not experienced before, it took two years for the flooring to be replaced during which time I felt unsafe in the bathroom, constantly worried I would fall if there was soapy water on the floor.

47. It also took around six months for the toilet lift to be repaired. During this time, I felt breathless and fatigued every time I had to go to the toilet because of the extra effort that was required while the lift did not function properly. I also experienced many months' delay in servicing other adaptations in my home namely my adjustable electric bed and my reclining chair. As a result, I avoided using the reclining chair completely. I still used the adjustable electric bed but only by keeping it at a fixed height. This made transfer from my wheelchair to bed, and vice versa, more challenging as for safety reasons I am supposed to move from a higher position to a lower position due to weakness in my pelvis.

48. Delays such as this were also experienced by other adult social care users who lived at home in the pandemic. In some cases, I am aware it made their home environment unsuitable for them, forcing them to live in unsafe housing that was not adequately accessible but there was nothing they could do about it. I know of cases where adult social care users had to be housed in unsuitable hotel accommodation because their homes became unsafe. There were other cases I heard through the DR UK Helpline of people who had become Disabled as a result of an accident but not suitably rehoused.

49. I know of a woman who is recognised as a refugee and is Disabled who also suffered from muscular dystrophy and is a wheelchair user. She was placed in a hotel with no kitchen which had impacts on her health given the quality of food available in place of home cooked healthy meals. Her accommodation was also not accessible, it had steps to get in and out. She relied on a manual wheelchair and could just about manage the steps with help from others – if they would offer to help - but there was a risk of her falling out of the chair when doing so. She was only supposed to be there for 6 months but remained there for two years during the pandemic. I know her health deteriorated as a result of all of this.

Access to PPE

50. I faced a number of problems with access to PPE. Firstly, there was the problem of delay. It took until the summer of 2020, maybe June or July 2020, before I received a letter from my Local Authority saying that I could access PPE from them. Prior to this, I had to buy my own PPE, and PPE for my PAs, from a local pharmacy which was in short supply. In time, I managed to source face masks, aprons and gloves but only in small quantities. Also, there were supply problems which meant I was not able to source sufficient quantities of small sized gloves which one of my PAs needed. The masks were also the very basic disposable face masks as opposed to more effective masks.

51. I also faced difficulties in how the PPE was provided. Firstly, whenever I requested PPE, it was only delivered the following Monday so could not be provided at short notice. Secondly, the people delivering PPE would not bring it into my home and there were times the boxes were just left in the communal parts of my block of flats so someone else would need to collect them for me. For me this was inconvenient as family members would need to collect it but for others who live alone in flats, they would not have been able to access it without some other support.

Difficulties for new applicants and with other changes in personal circumstances

52. On the helpline we were often contacted by people who were new to the adult social care system who found it difficult to access social care funds as new applicants. Many were disadvantaged by delays that worsened during the pandemic and were unable to access the social care support they needed.

53. Another detriment I found that adult social care users faced more in the pandemic was when they wanted to move from one Local Authority to another. In those cases, there was often a failure of the Local Authorities to communicate properly with each other resulting in the Disabled people not being able to 'port' their full care package from one to the other and suffering a break in the continuity of their care package when they moved. This happened, for example, where students had to cease residing at a university and move back home to study on-line. In addition, where there was a change in circumstances which meant a different level of care support was needed in the new Local Authority, this was often not met for considerable periods of time.

54. There were also problems in the pandemic faced by older children who were transitioning into adult social care but not receiving the adult social care they needed. Transition to adult social care can generally be a problem but this was exacerbated during the pandemic, resulting in delays and gaps in provision.

My older sister's experiences

55. My older sister Rania was severely disabled. She had muscular dystrophy and a heart condition similar to my own impairments, but as the condition is progressive her symptoms were much worse than mine. She also did not have the use of her right hand. She was a wheelchair user.

56. Her care package was much more extensive than mine; she had a greater number of hours' support from PAs. She could not feed herself or care for her own personal hygiene and a hoist (requiring two PAs) was needed to move her. She received funding from two sources: from the Independent Living Scheme and from the Local Authority. Although the Independent Living Scheme was closed to new applicants in July 2015, she still benefitted from it as a pre-existing recipient.

57. She was not married and had no children, so she was completely reliant upon the care and support she received in her home from her PAs. She was visited by two PAs at a time in the late evening and in the morning. One pair would visit her for 2-3 hours in the very late evening to change her, care for her hygiene and get her into bed using the hoist. The other pair of PAs attended in the morning for 2-3 hours to get her out of bed with the hoist, shower her and change her. In the daytime she was also visited by a PA working on their own to cook, clean and feed her. This PA could visit alone as they did not need to use the hoist. Although Rania lived with my parents, they could not help given their own frailty.

58. I am aware that due to the reduction in care services made available to her during the pandemic there were occasions when Rania's usual PAs could not attend. At worst, this resulted in her having to sleep in her wheelchair or not have anyone to wash her and care for her personal hygiene where she had wet herself or soiled herself.

59. In those circumstances, and for emergencies, it was vital that there could be a pool of PAs, one of whom could step in, but no such pool existed. All the PAs she knew were reluctant to work with new people during the pandemic to avoid the risk of infection and wanted to keep within their existing bubbles. All of this put a huge amount of emotional strain on her.

60. Once lockdown was imposed in March 2020, I only saw her once at her home before in June 2020 she was admitted to hospital suffering from breathing problems. She remained there for about a month before being discharged. During that month when she was in hospital my mother and I could only see her on two or three occasions. She was discharged in late June or early July 2020 and died on 2 August 2020 around a month after being discharged home having suffered from pneumonia. There was a post-mortem conducted even though that was against the family's wishes. It meant her burial was delayed beyond the 24 hours within which we wished for it to happen for cultural and religious reasons.

61. For her funeral, we were only allowed to have 15 people in attendance at Regent's Park Mosque. Her untimely death and the experiences she suffered in the months before she died have had a lasting impact on me and the rest of my family. If there had been better planning for her care in the event of a pandemic, her quality of life could have been so much better in the months before she died.

My younger sister's experiences

62. My younger sister is 43 years old. She is blind and has severe learning difficulties. She can only say a few words with which she can form only a few sentences and phrases. Her comprehension is also limited. She requires 24-hour care and cannot live on her own. She first moved into supported living around 25 years ago and lives there with three other women. They all receive support from care workers commissioned by the Local Authority.

63. Nobody in our family could see my younger sister for very many months in the pandemic. Ordinarily, we would see her on a weekly basis at least once or twice. We missed her dearly and she was very upset that we could not meet face to face. She struggled to understand why we could not see her face to face. Our contact with her was limited to phone and video calls but she could not communicate with us properly using those devices. Our communication really requires face to face conversations where we can hold each other, and she can use 'touch'. My parents missed her very much and the whole family regret that from early in the pandemic my younger sister did not see our older sister and so she did not see her in person at all from then until her tragic death.

64. My younger sister would generally love going outdoors but she was not able to do this in the pandemic for many weeks due to social distancing regulations. Staff in her accommodation did not want her to go outside to have any risk of catching Covid-19 from anyone else. She became very frustrated being indoors. She used to go to parks and attend an Adult Education Service which had a floor set up for people with learning disabilities. She would take craft and music lessons and had been doing a course at the Adult Education Centre which would improve her communication skills, but she had to stop doing all of this. Her support workers in the home tried to compensate by showing her educational videos and teaching her simple things like how to make a sandwich or breakfast. She seemed more willing to learn these skills being stuck indoors but she missed out on a great deal of developmental opportunity with the closure of her Adult Education Service.

65. Not being able to go out at all had several other negative impacts on my younger sister's wellbeing. She became more confused and frustrated. She would get angry, and her behaviour became more challenging. She also became more withdrawn and sought to isolate herself. As a result, by around May 2020 we asked the manager of her home to take her out. Eventually, maybe 2 months after that, the manager had a meeting with Social Services

and they all agreed that they would take her out to parks on the basis that she would not go to any indoor locations such as shops or cafes (which she previously loved to do). The pandemic was new to everyone and staff were working hard and at risk so I can't blame them for being risk averse. However, I believe her escorted visits in the open air could have been arranged much sooner and some central or local government guidance on this in advance, which emphasised the particular needs of people with certain impairments such as learning disabilities for outside exercise, would have helped. As it was, while other people were eventually able to go outside, others such as my sister in supported living were prevented from doing so.

66. I am aware there were restrictions on the number of people her care workers could have contact with to reduce the risks of the virus spreading to her accommodation. In the early days of the pandemic a care worker contracted Covid-19 and the home did not find anyone to cover her work for some time which was very upsetting for her and meant she became withdrawn just watching TV. However, over time the home did make alternative arrangements to maintain the right level of staffing through employing seasonal workers. Thankfully my sister did not, as far as we are aware, contract Covid-19 or at least she has never been symptomatic. This suggests to me that the home was managing infection prevention and control well.

67. My main criticism of my sister's care would be that I don't think enough was done to explain to her why she was being prevented from seeing me and the rest of my family or about the pandemic in general and what it meant. I could have explained this to her if allowed to see her face to face. I would have been very careful to take precautions before seeing her and in my view, consideration should be given to permitting at least one designated family member access to someone in my sister's situation to enable them to properly understand what is going on and to maintain even a small amount of the human contact that is so vital to their wellbeing.

Experiences of providing care to elderly parents

68. My parents are 75 and 83 respectively. They are relatively mobile and can make some simple food for themselves but in older age they have become frail with arthritis and can do much less than they used to. My father is visually impaired and my mother suffers from Parkinson's disease. As a result, they receive Attendance Allowance, which is a benefit for people over State Pension age who need help with personal care because of an illness or disability. Prior to the pandemic while they were living with my older sister, I would have food sent to them each week which had been cooked with the help of my PAs. During the pandemic this was not possible, but my sister found an organisation that could deliver ready-made meals for them.

69. After my sister's death, my parents moved in with me in September 2020 and my PAs would generally assist with their meal preparation in carrying things and chopping foods.

70. Prior to the pandemic my parents would also attend two local community centres, the mosque and their local library but these were closed at various times during the pandemic, so they were stuck indoors with nowhere to go and this added to the responsibilities upon the rest of us in the flat to care for them.

71. In my view the main difficulty they faced in the pandemic was reduced access to healthcare appointments. I could not arrange face-to-face appointments with the GP for them. My father was due to have a hernia operation, but this was postponed. It took many months before the hospital could tell me when he would have his operation. Ultimately, the operation was a year late and so he remained in unnecessary pain for a year.

Ongoing impact

72. I suffered Covid-19 during the pandemic, but it was relatively mild compared to others. However, my own personal experiences as I have described in this statement, and the fear and uncertainty during the pandemic have all had a lasting effect on me, as has the loss of my older sister. I also lost a dear friend of mine who was a neighbour and another relative who died shortly after my sister passed away.

73. During the entire period the Inquiry is examining by its Terms of Reference, from January 2020 to 28 June 2022, my care package was only assessed once and therefore only uprated for inflation once, this happened in May 2021. This followed a telephone assessment. The cost of living rose considerably during that period which made it much harder for my PAs to survive on what I paid them. I still worry that low rates of pay will not be sustainable for PAs in general, especially in London. In London I believe pay for PAs should be at least £15.00 per hour (ideally more) but it is currently £13.15 per hour for my PAs as I am awaiting an annual assessment and even after that assessment it only likely to increase to £13.85.

74. There has also been a general trend in annual reviews of my care needs that makes me feel like the questions I am asked are more intrusive and designed to find ways to cut my Direct Payments as opposed to finding ways to properly support me. This is despite the fact that they should expect my needs, and the payment I receive, to increase as time goes on because, firstly, my muscular dystrophy is a progressive condition which worsens over time and, secondly, the cost of living keeps rising at a much greater rate than it used to. Wages across society have had to increase to enable people on low incomes to make ends meet and this is the case as much for PAs as it is for others on low incomes.

75. Regarding services for adult social care users, many day and respite services across the country remain closed which has put yet more strain on an already minimal and threadbare system of support. The current climate towards Disabled people who are adult social care users is a very hostile one with a great deal of fear that the reductions in support implemented during the pandemic will never be reinstated and the situation will only worsen further with impending cuts.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Personal Data

Dated: 12 May 2025