Neutral Citation Number: [2024] EWHC 3063 (Admin)

Case No: AC-2024-LON-000800

IN THE HIGH COURT OF JUSTICE
KING'S BENCH DIVISION
ADMINISTRATIVE COURT
SITTING IN LONDON

Friday, 6th December 2024

Before:
FORDHAM J

- -

Between:
THE KING
(on the application of DAISY SIMPSON) **Claimant**
- and -
NHS MID AND SOUTH ESSEX
INTEGRATED CARE BOARD **Defendant**

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Jamie Burton KC and **Tim Baldwin** (instructed by MJC Law) for the **Claimant**
Lee Parkhill (instructed by Mills & Reeve) for the **Defendant**

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Hearing date: 14.11.24
Draft judgment: 25.11.24

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Approved Judgment

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FORDHAM J

This Judgment was handed down remotely at 10am on Friday 6 December 2024 by circulation to the parties or their representatives by email and by release to the National Archives.

FORDHAM J:

Introduction

1. This case is about the legal adequacy of provision made by an Integrated Care Board (ICB) for the care of a person eligible for NHS Continuing Healthcare (CHC).

The Claimant

2. The summary which I set out below was commended to me by Mr Burton KC and Mr Baldwin. It originates from a review which the Defendant conducted in September 2023. It was included within the Defendant's care plan dated 12.4.24 ("the Plan"). A "portacath" is a small piece of medical equipment that can make receiving frequent doses of intravenous (IV) therapy over a long period easier for healthcare professionals and more comfortable for patients. BIPAP is a form of non-invasive ventilation.

> ***Daisy is a 35-year-old lady that lives alone in a one bedroomed flat in Brentwood. She is currently in receipt of a personal health budget with which she employs carers over a 24-hour period. Daisy has a long history of mental health disorders diagnosed at the age of 17 and numerous physical health conditions including Diabetes, Gastro issues, Gynae issues, Chronic Lung Condition, Moya Moya disease, Recurrent Trans Ischemic Attacks (TIAs) and Sleep Apnoea.***
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> ***Daisy has multiple interventions to support her breathing including BIPAP, Nebulisers six times daily, a four weekly intravenous infusion, a flutter device (a type of cough assist) and oral medications. Her fluctuating physical abilities mean that she often struggles to manage these interventions without support from her carer. Her carer also prepares all meals for Daisy and when she is present will also serve them to her. Daisy reports that she experiences intermittent swallowing problems especially following a TIA. Currently Daisy can access the toilet to pass urine and open her bowels however, she suffers from both incomplete emptying, requiring intermittent self-catheterisation at least once daily, and bowel dysmotility causing her issues with constipation that did require self-administration of enemas, however, this now appears to be managed with administration of Bisacodyl oral tablets. Daisy is at risk of skin deterioration due to her reduced mobility and as a side effect of oral steroids. She requires assistance from her carer to maintain her skin integrity. She has pro shield barrier cream applied at least twice daily. Daisy has a history of having suffered a stroke leaving her with left sided weakness. She is, however, still able to weight bear using pivot transfers although she stated that this is becoming more difficult each time, she has a further TIA. Currently Daisy requires the assistance of one to two people to assist her with the transfers. No falls have been recorded. Daisy has an electric wheelchair which she can drive herself once she has been assisted into position. Currently this is only used for outside purposes as her home is reported to be too small for wheelchair use.***
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> ***Daisy can verbally communicate clearly and articulately although she can intermittently suffer with mumbled speech especially after a TIA. Currently Daisy is orientated to time, place and person and has good insight into her impairments however, her memory is reported to have been worsening of late to the extent that she now requires prompting with all day-to-day activities. Daisy denies any challenging behaviour and states that she will only say no to something if she feels that she is being put at risk.***
>
> ***Daisy has a complex medication regime which she currently manages herself with assistance from her carer although she stated that she is finding this more difficult. She has purchased an Insulin Pump and a constant glucose monitor to manage her diabetes. She requires assistance from her carer to fill and set up the pump and from her carer to enter carbohydrate amounts and blood sugar readings into the pump for it to calculate bolus doses. Daisy is prescribed Codeine to manage her pain however, she reports that this is ineffective, and she suffers constant pain. Oramorph is prescribed for breakthrough pain relief and Daisy can request this from her carer when needed. Daisy has also recently been diagnosed with Endometriosis which causes her to have heavy bleeding from her vagina. She requires assistance from her carer to manage this at***

> ***times. Daisy is extremely difficult to cannulate and has now had a portacath inserted for easy vein access.***
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> ***Daisy suffered a stroke in 2021 and has been diagnosed with Moya Moya disease which limits the flow of blood to her brain and puts her at risk of further strokes. Daisy stated that currently she is having TIAs daily which temporarily affect her speech, mobility, and cognition. Daisy has multiple conditions affecting her daily life …: Moya Moya disease (under the Bristol, awaiting cerebral vascular bypass operation); Admissions to Queens with stroke and sub-arachnoid haemorrhage; Brittle asthma (under Brompton Hospital); Obstructive sleep apnoea (BIPAP) (under the Brompton); Diabetes Mellitus (presumed type 1, insulin treated, supported by the diabetic nurses); Recurrent episodes of elevated lactate levels (uncertain cause); Schizoaffective disorder; Migraines; Cushing's syndrome from previous long term steroid use. Presumed adrenal suppression due to long term high dose oral therapeutic steroid use; Progressive multiple fatty lumps; Emotional Unstable Personality Disorder. Daisy is known to multiple services including: Neurosurgeon; Respiratory physician; Gynaecologist; Ophthalmologist; Consultant neurologist - Dr De Silva; Dermatology; Diabetes and Endocrinology - Basildon and Thurrock Hospital; Occupational Therapy for support and equipment.***

3. In her first witness statement, the Claimant gave me this summary of her needs:

> ***I have a life expectancy prognosis of 1-2 years. So, for every minute that passes, I am dying. My already vastly reduced life expectancy is diminished for every day that I am not able to receive a personalised package of NHS Continuing Healthcare … that meets my physical and mental health needs in the immediate future… I have a number of complex diseases which are so rare that, statistically, finding someone who understands my needs is nigh on impossible. For example, I have a condition called Moyamoya disease, which affects only one in every million people. This causes me to suffer from 17 Transient Ischaemic Attacks ('TIAs' / strokes per week (i.e., 3 per day), which significantly hampers my quality of life. Any of these stroke episodes could ultimately prove fatal.***
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> ***Amongst other conditions, I have severe asthma; excessive dynamic airway collapse; type 1 diabetes; and sleep apnoea, for which I receive a large amount of medication and medical equipment that needs to be administered every day. My medication dosages change and titrate daily. I have different antibiotic regimen and steroid doses. I have some medications that must be given in an emergency and are time sensitive. Carers alone cannot make the clinical judgments to respond to the different needs in a safe way. I have multiple different clinical needs. To treat me and give me the correct medication, there needs to be ongoing clinical assessment. There is no way to care plan all my 30+ healthcare conditions that reduces the need for clinical judgement.***
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> ***My carers are having to administer medication to me, despite having no clinical expertise. I receive high-risk medication – for example, insulin, morphine, and codeine – none of which is clearly documented. This has meant that my carers have overdosed me with insulin and morphine due to not anticipating the complexity and intensity of my needs. My medication regime often changes on an hourly basis. Without 24/7 nursing provision to ensure that my care regime is safe, I am terrified that my carers could overdose me. If my carers walked in and found me drowsy – which is not unusual, given my needs – that could stem from multiple different clinical needs; or even a combination of needs. For example, stroke, brain bleeds, seizure, hypo, hyper, adrenal suppression / failure, infection, and respiratory failure. In my case, these all have different management and treatments; and if the carers treat me for a stroke and miss a hypo, my conditions then end up mimicking each other. It is too high risk for carers to be making judgments unaided.***
>
> ***Given the rarity of my conditions, whenever I seek care from healthcare professionals from day to day, they generally do not have the experience and do not understand any of my conditions. It is difficult to find someone else like me across the board. That makes the issues in my care challenging because there is no set standard for what the care should be – as it is so rare and complex, professionals have no benchmark, no comparator, on which to base my needs. So, many of the complexities in my care stem from the diseases I have got being very difficult and very rare, based within a system that is not set up for someone with the level of rarity and complexity of my diseases.***

> ***So, a lot of my care is based at national services: tertiary care providers. Tertiary care providers are removed from secondary care services – they are highly specialised. In adult care, they are generally spread out across the country. Most adults, if they are unfortunate, would end up under just one or two of these specialised services. Due to the uniqueness of my conditions, I have ended up under multiple specialist services spread out across the UK – all dealing with professors and specialists who are top of their field in their area. However, this has left a massive crater in my care at a local level because my needs are deemed "too complex" for secondary care – which is what the ICB commission and what local services commission – so that is why I am under national providers. However, the national providers are also terrible at speaking to each other as they are all under different systems (for example, System One, System Two, EPIC, amongst others).***
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> ***Part of the breakdown in my care is not just the complexity and the actual conditions themselves, but also how those conditions are managed and how they are now spread out across the entirety of England. There is no professional bringing this together; and so, complexity is used within that to deny needs and pass the buck onto different sectors of the NHS. It strikes me that the ICB has done this time and time again in order to deny the full scope of my needs. It tells me to speak to my GP, who then refers me to other services within the NHS, who cannot assist me on grounds of complexity.***

4. This is taken from what the Claimant told me about her hospital appointments:

> ***I am under something like 35 different clinical teams. Every time I see a doctor, they refer me to another set of doctors – hence why I am under so many different people. I am having to travel frequently to London, Cambridge, and Bristol. I am travelling almost all the time. As part of my previous care and support plan, I was getting overnight stays for hospital trips. I was also getting transport costs covered. This was agreed due to the sheer amount of ongoing hospital appointments I have got. At the time the ICB assessed me, I had 18 appointments in 30 working days. These were long-distance appointments. Some weeks, I am at multiple appointments in one week. It has not been unheard of where I have been in London, Cambridge, and Bristol all in the same week…***

The Flat

5. Mr Burton KC showed me photos of the Claimant's flat. I saw the bedroom with the bed, some cabinets and equipment, and a swivel chair. I saw the living room with a temporary bed and double-seater settee, some shelves and storage boxes, and the Claimant's electric wheelchair.

Previous Care Coordinators

6. Maria Whelan was an employee of the Defendant who acted as a care coordinator for, among others, the Claimant. That was until February 2023. Katie McIlroy was an employee of the local mental health trust who also acted as a care coordinator for, among others, the Claimant. That was for four years until 2023.

The PA

7. Charlotte Duggan was recruited by the Claimant as administrative support. Ms Duggan has become a full-time personal assistant (PA) for the Claimant. This is an extract from what Ms Duggan wrote for the Defendant on 25.3.24 about her role:

> ***I am Daisy's Administration Support as the administration side of Daisy's complex situation is substantial as you can imagine. I also cover everything HR related. (Employment, Contracts, Sickness, Holiday, etc). I was initially employed to take the pressure from Daisy and deal with all paperwork, arranging clinical appointments, and supporting Daisy with anything Administration related. It quickly became apparent that she needed help with HR Duties and a Lot of***

> ***complaints/issues etc which in turn took over my role completely. I find that most days we are dealing with issue after issue, [setback] after [setback], chasing professionals for responses, begging for help on Daisy's behalf. This was taking me away from what I was employed for on 30 hours a week. I work around 40-45 [hours] per week for Daisy now in order to complete what is needed and even then it's not always completed. I have worked in one of the busiest NHS A&E departments and I can honestly say that I am far busier In this role for Daisy, the paperwork and complex nature of everything makes it a lot more chaotic and I would hate to think how Daisy would be coping without me.***

The Office Space

8. Ms Duggan said this to the Defendant about the nearby office space which the Claimant has rented, at a cost of £1,440 per month:

> ***Daisy rented an office space within a 1 min walk to her flat. She did this for the following reasons… The confidential paperwork that I deal with daily would have been lying around in my house and I do not have space for an office. My house is a very busy house with 1 teenager and 2 small children. All paperwork is now safely filed at the office and can be referred to easily. It's within a 1 min walk to Daisy so I can go and consult with her as necessary. Carers can come there for breaks/shower and changeover etc, this saves more people than necessary being in Daisy's flat at one time. Weekly Team meetings are held in the office. Job interviews are done in the office. The office space has been a great addition to the team in every way.***

9. The Claimant's solicitor is Ross Peters at MJC Law. He gave the Defendant this description of the office space in an email dated 25.3.24:

> ***Office space – Ms Duggan and [Ms Simpson's] carers utilise the office space – it is used predominantly for team meetings, HR meetings, disciplinary concerns, interviewing new care staff, confidential telephone calls, vetting, training, and storing confidential paperwork. You will be aware that privacy is of the utmost importance to Ms Simpson … She has also been trapped in one room for the last three years; hence, she would not be able to fit two carers and a clinical case coordinator into her flat. Otherwise, Ms. Simpson considers that she would be exposed to safeguarding risks; for example, she would have to interview new care staff and manage the administrative aspects of her care provision from her bed, which is an unjustified interference with her personal space… [T]his goes directly to her health and wellbeing outcomes.***

CHC

10. CHC is a package of care arranged and funded solely by the health service for an adult individual, to meet physical or mental health needs which have arisen as a result of disability, accident or illness: see the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 (SI 2012/2996) reg.20. The Claimant is entitled to CHC arranged and funded by the Defendant as the ICB to meet her reasonable requirements for – in particular – medical services, nursing services and other services or facilities for care considered by the Defendant appropriate as part of the health service. That position is derived from the Defendant's general (or target) duty in s.3 of the National Health Service Act 2006; the eligibility and needs assessment duties in reg.21 of the 2012 Regulations and the National Framework to which the Defendant is obliged to have regard (reg.21(12)). The essential question for the Defendant is this: what provision is reasonably required to meet an assessed health and care need within the CHC? The Claimant's lawyers accept that the Defendant has asked itself the right question. The issues are about whether it has answered that question lawfully, which means reasonably and after a reasonably sufficient enquiry.

11. It is common ground that "facilities" for "care" (s.3(1)(i)) could in principle involve an ICB paying for accommodation, if that were assessed as reasonably required for making provision to meet relevant needs and an appropriate part of the health service. I was shown the observations of Vos LJ in R (Whapples) v Birmingham Crosscity Clinical Commissioning Group [2015] EWCA Civ 435 [2015] PTSR 1398 at §46. No question arises in the present case about care and support needs being met by the local authority rather than the Defendant. Such questions can arise: see the National Framework (July 2022) at §318. My attention was invited to the National Framework at §§55-59 (primary health need); §§187-193 (case management and care planning); §208 (well-managed needs and reviews); §303 (higher cost care packages); §§315-319 (supporting individuals eligible for CHC in their own home); and §§320-326 (personal health budgets and equipment). Reliance was placed on the Defendant's PHB Policy (Personal Health Budgets: Ethos, Practice & Guidance 1.7.22) at §§6.3.13 and 6.3.14:

> ***Use of community services. 6.3.13. PHBs should not be used to purchase services that the ICB already commissions, including community health services and equipment. Any exception to this would need to be considered by the ICB on a case-by-case basis. 6.3.14. During the care and support planning process the individual (or their representative) will be informed of existing NHS services.***

Direct Payments

12. CHC in the present case is provided by direct payments for services specified in the Plan. The Claimant is statutorily-obliged to use the direct payments only for services specified in the Plan: see reg.11 of the National Health Service (Direct Payments) Regulations 2012 (SI 2013/2017). I was shown NHS England's Guidance on Direct Payments for Healthcare: Understanding the Regulations (5.12.22) at §3.3, addressing what a direct payment can be spent on.

13. These are ways in which an ICB making direct payments can decide to allow flexibility. First, it can formulate a plan to allow for decision-making choices or headroom. Secondly, it can revise the Plan. Thirdly, it can agree to allow a different use of the allocated money (the financial envelope) from the one which has been specified in the Plan. Mr Parkhill locates the last of these as being the power to desist from any enforcement action including stopping ongoing payments (as to which see reg.17(2)(d) of the 2013 Regulations).

14. The impugned decision letter in this case is dated 12.4.24. It was written on the Defendant's behalf by its solicitors. This is what it said about flexibility:

> ***The enclosed plans do not contain any provision beyond that which the ICB has determined is reasonably required to meet assessed needs. If the Claimant would like to discuss the detail of the plans and/or explore the option of including additional provision within the PHB plan aimed at enabling her to achieve health and wellbeing outcomes, then the ICB is happy to engage with her, via email for that purpose.***
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> ***As a general principle, the ICB will only fund this additional provision from within the indicative budget financial envelope. This is because the indicative budget reflects the cost of the care the Claimant is assessed to require were it to be commissioned directly by the ICB. The indicative budget therefore provides both a financial envelope which is adequate to meet assessed need and a way for the ICB to manage its finite NHS CHC resources equitably for all NHS CHC recipients.***

Public Law

15. Because this is a claim for judicial review, I am exercising a secondary supervisory jurisdiction, deciding questions of law. These are key points about the application of relevant public law principles, relevant to the present case:

    (1) When it assesses needs and identifies arrangements to meet needs, an ICB is entrusted with making evaluative judgments: about what the individual's reasonable requirements are; about what services and facilities are appropriate to meet their relevant needs; and about what services or facilities for care are appropriate as part of the health service. These are all evaluative judgments for the ICB as the primary decision-making authority. The High Court has no function of substitutionary review. Instead, the Court applies conventional standards of reasonableness review, See Wahid v Tower Hamlets LBC [2002] EWCA Civ 287 [2003] HLR 2 at §33; and Lambeth LBC v Ireneschild [2007] EWCA Civ 234 [2007] HLR 34 at §44.

    (2) Those conventional standards of reasonableness review involve asking: (a) whether the outcome is beyond the range of reasonable responses; (b) whether the reasoning process involves a recognised species of error of approach (eg. an error of logic or the disregard of an obviously relevant consideration); and (c) whether there was an insufficiency of reasonable inquiry. See R (Law Society) v Lord Chancellor [2018] EWHC 2094 (Admin) [2019] 1 WLR 1649 at §98 (as to (a) and (b)); and Balajigari v SSHD [2019] EWCA Civ 673 [2019] 1 WLR 4647 at §70 (as to (c)).

    (3) Decision documents including needs assessments and care plans are read and approached with an understanding of their nature and function, avoiding over-zealous or legalistic examination. See Ireneschild at §57.

    (4) A judicious balance must be struck. On the one hand the necessary intensity of review is high and the scrutiny close, given the profundity of the impact and since provision of a global sum may make a failure to meet eligible needs less visible. On the other hand, the judicial review court must respect the functional distance between primary decision-maker and secondary reviewing court, recognising the prospect of judicial blind-spots and avoiding inappropriately over-exacting demands. See R (KM) v Cambridgeshire County Council [2012] UKSC 23 [2012] PTSR 1189 at §36.

These Proceedings

16. This judicial review claim was issued on 6.3.24. It was issued "protectively", after the Defendant had made a previous decision on 6.12.23. The issuing of the claim stopped the clock. But the parties agreed to make space for a fresh decision. By consent, there was a stay of these proceedings, with Court-directed deadlines for: (a) representations and evidence from the Claimant's representatives by 15.3.24; (b) a decision by the Defendant by 12.4.24; and (c) any application to lift the stay by 17.4.24. The parties had agreed that these proceedings would be a vehicle for any challenge to the new decision, on amended judicial review grounds. The Defendant's impugned decision of 12.4.24 was arrived at within this litigation framework. Amended grounds were duly filed on 19.4.24, and on 6.6.24 the Court directed a "rolled-up" hearing which was fixed for 15.11.24.

About the Decision-Making Process

17. Here is how the decision-making process is described by Carolyn Lowe, the Deputy Director of the Defendant's All-Age Continuing Care, Nursing and Quality Directorate:

> ***The ICB committed to continuing the care and support planning exercise with a completion date planned for 12 April 2024. Ms Simpson was to provide further information or evidence for consideration by 15 March 2024 and that fact was recorded on the face of a court order. This was to give Ms Simpson time to gather any information and the ICB sufficient time to consider it. Ms Simpson declined requests for a meeting in person or remotely and requested the ICB only communicate with her via email, predominantly via her personal assistant Ms Duggan. Ms Simpson's lawyer expressed that such a request should be accommodated as a reasonable adjustment. The ICB agreed to accommodate this request. Ms Simpson's solicitor filed a witness statement on 8 March 2024 exhibiting various documents which the ICB were to consider as part of its review, which it did. Ms Simpson also continued to supply information in support of her views as to needs beyond 15 March 2024, to which the ICB has continued to have regard. Additionally, as part of the care and support planning process, registered nurses Kim Oddy and Nicola Wood, who are the ICB clinical case managers assigned to Ms Simpson, contacted professionals involved in Ms Simpson's care and treatment for further clarification around care plans and Ms Simpson's needs. They also reviewed her electronic records on the SystmOne and Broadcare systems, as well as the documents submitted by Ms Simpson and the review from September 2023. Nicola Wood emailed Ms Simpson via her personal assistant Charlotte Duggan for any information gaps that they were unable to find and to seek clarification on information as needed and information provided informed the process. Kim Oddy, to prepare draft PHB plans, contacted Ms Simpson via Charlotte Duggan to identify her current staff and pay rates, what PPE Ms Simpson requires, the costs of PPE, her payroll provider and the associated costs. Kim Oddy requested the cost of the Payroll services three times, but has not yet received this information. Kim Oddy also worked with the brokerage Purple to prepare two draft PHB plans, one using Ms Simpson's current rates of pay and one at the market rate. Professionals contacted included, Ms Simpson's Occupational Therapist, Speech and Language Therapist, her GP practice, her specialist Moya Moya Consultant, her Diabetes team, NHS Continence Services and the respiratory specialists at Royal Brompton regarding asthma. The ICB also had regard to recommendations in the independent review it commissioned regarding Ms Simpson's needs and care and support within the period of 7th March 2022 to 31 May 2023.***

Fresh Evidence

18. There was an uncontentious procedural point. It related to the three rounds of witness statements on both sides: three from the Claimant; and three from Ms Lowe. These statements were accompanied by exhibits. All of this evidence post-dated the April 2024 decision which is the target for judicial review. The parties were agreed about two things. One was that there was no basis for shutting out any of this evidence on the basis of any unfairness, non-compliance or lack of procedural rigour. The other was that the legal relevance of the evidence could be considered by the Court by reference to the content. I gave permission, on this basis, for all of the evidence to be adduced.

Alternative Remedy

19. There was a contentious procedural point. The Defendant argued that its internal complaints mechanism was an appropriate alternative remedy which should be exhausted before bringing public law issues before the Court. The Court of Appeal had emphasised in Ireneschild at §82 that: "It should not be overlooked that there is a statutory complaints procedure which can be used by anyone who is aggrieved by his or her care or assessment plan". Mr Parkhill cited R (S) v Hampshire County Council [2009] EWHC 2537 (Admin) and R (F) v Wirral Borough Council [2009] EWHC 1626 (Admin). No doubt preserving the Defendant's ability to raise this discretionary bar was part of the thinking behind a

rolled-up hearing. Mr Burton KC and Mr Baldwin urged me to decide this claim on its legal merits. And that is what I have decided to do. It may be – with hindsight – that greater latitude within the consent order for the stay, or an agreed second short stay, could have allowed a speedy internal review which could have been to everyone's advantage. But litigation lines were drawn, within a framework of an agreed decision-making timetable after an agreed stay. The Claimant's representatives could not risk allowing the proceedings to lapse by missing the deadline of 17.4.24 to apply to lift the stay. That was the agreed course open to them if they wished to advance a legal challenge. Moreover, it remained open to the Defendant to review the decision at any time, as indeed it did on 29.10.24. This case has been prepared and argued in full in the High Court. In the special circumstances of this particular case, I do not see it as promoting the interests of justice or the overriding objective to send the Claimant away without a ruling on the legal merits of the issues of law which she has raised. I decline to dismiss the claim on the alternative remedy ground. As it happens, there are parallels with the origins of Ireneschild itself: see [2006] EWHC 2354 (Admin) at §31.

The Package of Care in Overview

20. The impugned decision on 12.4.24 assessed the Claimant as having relevant needs, to be appropriately met, by means of round the clock (24/7) 2:1 care by two carers, costed at £17 per hour in the daytime and £19 per hour at night; and in addition a full-time (37.5 hours a week) clinical care co-ordinator/case manager ("CCC"), costed at £25 per hour. The Plan identifies the required role of the CCC as being to:

> ***[i] Co-ordinate appointments ie. all admin involved including phone calls. [ii] Liaise with medical teams to co-ordinate care (including provision of equipment) and ensure all teams have up to date information. [iii] Attend hospital and other medical appointments. [iv] Supervise and support PAs including ensuring all staff training is up to date, they have completed care competencies and online/face to face training, complete rotas, support with timesheet completion and any other admin relating to staff that is required. [v] Escalate any medical concerns to the appropriate teams. [vi] Collate/write care plans and ensure all information in them is keep up to date in consultation with other relevant professionals.***

21. The previous provision by the Defendant had been round the clock (24/7) 1:1 care from 21.3.22; and then 2:1 care in the daytime and 1:1 at night-time from 6.12.23. The impugned decision allowed for equipment: Gloves; Aprons; Masks; Wipes; and Anti Bac Spray (costed at £3,740.59 per annum). Previous funding for hotels, travel expenses and massage therapy was removed. By a subsequent decision on 29.10.24 funding for respite stays and paid advertising to recruit the CCC was allowed.

Nursing Care

22. The claim for judicial review focused on seven topics. The first is nursing care. Mr Burton KC and Mr Baldwin submitted as follows.

    (1) The Defendant's impugned decision of 12.4.24 fails lawfully to address the Claimant's relevant needs for the care of a nurse within her home. The Claimant has a clearly evidenced need for nursing care, which moreover needs to be around the clock (24/7). A 30-page schedule of unmet needs from the Claimant and her care team dated 2.4.24 clearly describes 24/7 nursing provision as needed in

relation to the following medical conditions or needs: ventilation; increased strokes/respiratory; infection lungs (including bloods, IV medication when required and fluids); strokes/TIAs (including IV fluids when needed); swallowing issues; communication issues; pain; endometriosis (including IV as required); the overall need for 24/7 nursing care (including ability to access IV fluids); bloods; and IV access. The Defendant has failed to identify any need for any nursing care, still less the 24/7 nursing care which is evidenced as needed. The CCC role description does not make any reference to the CCC undertaking any nursing care. The suggestion that – if necessary - the CCC as a trained nurse could take the Claimant's bloods via the portacath is made for the first time in witness statement evidence.

(2) There is the position as to dangerous drugs. There was clear evidence before the Defendant about the serious implications of dangerous drugs in the hands of unequipped carers. The Claimant's solicitor put forward a report by Lynn Jones at Health Advocacy (28.11.23) which described

> ***a number of life-threatening occasions where Daisy has received the incorrect medication or treatment as the carer was not equipped to manage the complexity of the situation.***

The Plan does not acknowledge the risks from dangerous drugs and does not even include Oramorph (morphine) within the 20 medications said to be "listed for the month of August 2023" on SystmOne (a clinical computer system); which fits with a pre-action letter of response (23.2.24) which had said: "There is no record of the Claimant being on morphine in possession of the ICB". Dangerous drugs need nurses to administer them.

(3) There is the position as to IV respiratory medication. The Plan identifies no provision for nursing care, including in relation to drug therapy and symptom control where the IV box is checked as applicable and the provision is a carer. Carers cannot administer IV respiratory medication. The Plan says:

> ***IV respiratory medication is administered via the portacath in a clinical environment only (The Royal Brompton).***

The point is that this would be administered in the home, except that the Defendant has failed to make provision for this. A post-decision letter of 24.6.24 from the Respiratory Consultant at The Royal Brompton to the Claimant's GP says: "we aimed to provide an antipseudomonal intravenous antibiotic at home". A post-decision email of 1.7.24 describes arrangements for "IV training for home antibiotics" with a "designated person". The Claimant's third witness statement (31.10.24) produces a plan on 8.4.21 for Basildon University Hospital to deliver, by its Hospital at Home team, IV Ceftriaxone. All of this is legally relevant fresh evidence, to demonstrate that there was no reasonable enquiry and to show what a reasonable enquiry of The Royal Brompton would have elicited.

(4) Finally, there is the position as to IV fluids. The Plan says:

> ***Monthly infusions for Asthma at the Royal Brompton. Daisy advised that she requires IV fluids in the community but there is no supporting evidence regarding the indication for this and Daisy's GP has advised via email that - IV fluids cannot be prescribed and monitored safely in primary care.***

The point is that the Defendant has confused a "who" question with a "what" question. The relevant email from the GP's surgery (which was dated 26.2.24) was recognising the "what" (that IVF fluids in the community were indicated) and the "who" (that prescribing would need to be by The Royal Brompton). In that email, the GP Practice Manager had written:

> ***I didn't go back to the ICB in the email about the IV fluids as we were asked at a meeting about it and we said that although we were aware you needed them it is not something we can prescribe in Primary care as its not available for GPs to prescribe - it's just not on the system - Brompton or whoever said you needed it originally would need to prescribe it as needs to come from a consultant.***

This email was in the Claimant's solicitors' representations bundle, together with a witness statement from the solicitor Mr Peters who described this as a document which:

> ***states that the Claimant does require IV fluids but that it is not prescribed in primary care; therefore, the ICB would need to engage with her consultants at Brompton Hospital.***

This alerted the Defendant to an inquiry which was reasonably required and which Ms Lowe's first witness statement asserts – but without any supporting evidence – was undertaken. The Defendant does not suggest that IV fluids can be administered by a trained carer or the CCC.

(5) In all these circumstances and for all these reasons, the Defendant's decision as to nursing care was outside the range of reasonable responses or involved a failure of the public law duty of reasonable enquiry.

23. I am unable to accept these submissions. I will explain why.

(1) The impugned decision letter started with this:

> ***In producing this document, the ICB has considered the further material provided by the Claimant in addition to reviewing material on her SystmOne records and information provided by professionals involved in her care and support. The ICB has not found the Claimant to have an assessed need for 24-hour nursing care.***

That was an evaluative judgment, as was the Defendant's consideration of various elements of needs and care.

(2) The CCC was specifically designed to be a qualified nurse, whose hours were costed as "Clinical Case Manager" and "Nurse Support".

(3) The letter of response of 23.2.24 is not a basis for a finding that the Defendant was in error as to morphine when it made its later decision on 12.4.24, giving an inclusive list (medication "includes"), and including an express statement elsewhere in the decision that "Oramorph is prescribed for breakthrough pain relief".

(4) The point made by Ms Jones about medication needs to be seen in its setting. As the Claimant's solicitor's witness statement of 6.3.24 accurately characterised it, the Jones report "outlined the critical elements of the Claimant's care and recommended an experienced nursing coordinator". The Jones report described

Katie McIlroy's previous role. That was the context for the point made by Ms Jones about drugs. Ms Jones said:

> ***Since the removal of Katie McIlroy (Care Coordinator) by the Mental Health Team there have also been a number of life-threatening occasions where Daisy has received the incorrect medication or treatment as the carer was not equipped to manage the complexity of the situation. No one has been put in place to take up all of the things Katie was doing and consequently the organisation around her care is in total chaos.***

Ms Jones went on to explain why a Nursing Care Coordinator was an essential requirement to provide: a Daily Care Plan which is cohesive and responsive to all medical and practical events; coordination of medical appointments including liaison with hospitals and clinical departments to ensure they fully prepared and have access to Daisy's care records; support for care staff for the more complex tasks resulting from unplanned daily events; training of care staff in the use of equipment which they may be unfamiliar with; and management of complex care provision.

(5) The Plan describes the CCC role as being "in line with the recommendation contained in the independent review and GP recommendation for a full time position". The GP's recommendation was in a letter dated 18.10.23 which described as beneficial "a nurse to support her care team", as a "case manager" who would "bring Daisy's care together", being someone with a clinical background to carry out this role given the Claimant's complex health needs. The independent review was a 30-page report dated 7.2.24, accurately described by the Claimant's solicitor as a review which "recommended the Claimant's need for nursing oversight". The independent review was recommending the following:

> ***A dedicated clinical resource could provide care coordination, support to avoid escalations or better manage escalations in care by monitoring and providing advice to the PAs delivering day-to-day care. In addition, some key tasks that cause issue such as the drawing of blood from the Individual's Port could be fulfilled by this function.***

Given the express reference in the Plan to this independent review recommendation, it is unsurprising that Ms Lowe's witness statement should describe the CCC, if necessary, taking bloods.

(6) The Plan records that specific consideration was given to both IV respiratory medication and IV fluids. As to IV fluids, it was correct that the GP Practice Manager had advised that IV fluids could not be prescribed and monitored safely "in primary care" (ie. by the GP). That is the "who". The Claimant's solicitor said the GP Practice Manager was stating that "the Claimant does require IV fluids". But that could only be a secondary understanding, as seen in the Practice Manager's references to "Brompton or whoever you said needed it". The Defendant was entitled to ask itself whether there was "supporting evidence regarding the indication for this". What had been elicited was that the Claimant had monthly infusions for asthma at The Royal Brompton. There are the post-decision communications from The Royal Brompton dated 24.6.24 and 1.7.24. But these are about IV antibiotics. And what this evidence shows is that The Royal Brompton's plan for IV antibiotics at home could be delivered by a carer with suitable training, which The Royal Brompton was arranging (1.7.24), as is the understanding described in Ms Lowe's third witness statement (7.11.24).

(7) I am unable to see any unlawfulness in the Defendant's approach to nursing care. I accept the submissions of Mr Parkhill on this part of the case.

The PA

24. The second topic concerns the PA. Mr Burton KC and Mr Baldwin submitted as follows. The full-time CCC role – which the independent review and GP were recommending – needed to be put alongside the very important functions already discharged by the PA Ms Duggan. Ms Duggan works full-time as PA, for £14 per hour. The new CCC role "subsumes" Ms Duggan's functions, as can be seen from the CCC job description in the Plan. But the CCC will be performing new functions not currently undertaken by the PA. This is clearly a 'PA-plus' role. The CCC's specialism as a qualified nurse is reflected in the higher hourly rate (£25 per hour). But the hours have not been increased at all, to reflect this 'PA-plus' role. The Claimant would be losing her PA, and gaining a CCC lacking the hours to discharge the PA functions. The CCC would have additional burdens. Indeed, the CCC's role is described as including attending all medical appointments, including all the time and travel. The Defendant nowhere addresses this obvious mismatch. How is this supposed to work? The PA's role cannot reasonably be assessed as subsumed within an expanded role, with other time-consuming commitments, without important but unacknowledged functions being lost. Nor is there flexibility to resolve this. The only flexibility could come from within the financial envelope, by reducing the full-time CCC function or the round the clock 2:1 carer functions, but these are assessed as necessary to meet relevant needs. It is illogical and unreasonable for the Defendant, in its reasoning, to contemplate the PA role being maintained through redistribution of what is in the allowed financial envelope. In all these circumstances and for this reasons, the Defendant's decision was outside the range of reasonable responses or involves a failure of logic in the reasoning process.

25. I am unable to accept these submissions. The Defendant has identified a full-time CCC role to meet the needs which it has identified. It fits with what the independent review and GP were recommending, as an integrated full-time role of a single individual. The assessment that the identified functions can be discharged by an individual acting full-time is an evaluative judgment. The CCC's hours of 37.5 hours per week have been assessed as sufficient. There will be ongoing review to ensure that the care and support provided is what is reasonably required. It is true that previously the Claimant has had the PA, Ms Duggan, alongside the care coordination functions of Ms McIlroy and Ms Whelan. But I am unable to characterise as unreasonable – as understood in public law – the Defendant's assessment that the job description (a) can be effectively delivered by an individual working full-time and (b) covers the administrative care and support required to meet the Claimant's relevant needs. I cannot accept that the Defendant's decision was outside the range of reasonable responses or was unreasonable for any other reason including a failure of logic in the reasoning process. I am unable to see any unlawfulness in the Defendant's approach to the CCC and administrative functions. I accept the submissions of Mr Parkhill on this second part of the case.

26. I add this. Mr Burton KC invited my attention to evidence about the difficulties in recruiting a person to the CCC role. But, in the end, this was relied on as relevant to the ability to place paid advertisements, which I was told the Defendant has agreed to cover from 29.10.24: and as relevant to the timing of two referrals (for a wheelchair and for slidesheets) to which I will return.

The Office Space

27. This is the third topic. Mr Burton KC and Mr Baldwin submitted as follows. The Claimant has a clearly evidenced need for the additional room she has been renting. It is a space which is needed for herself, for equipment, for her PA, and for each carer at different times and in different combinations. Her flat is too small. The Plan itself records that: "Whilst there is space in the living room for equipment to be stored, this will impede on the carers living space which Daisy does not wish to do". As Ms Duggan has explained, Ms Duggan's home is not an appropriate environment for storing confidential materials. The need for this additional space is all the greater under the arrangements which the Defendant has accepted. There will be the round the clock 2:1 carers, day and night. There will be the CCC on hand, during the day-time, to discharge the functions in the Plan job description and – as is now accepted – tasks like taking bloods. There is the bedroom and a small living room seen in the photos. It is simply too confined a space for two carers, let alone with the CCC as well. How is this arrangement supposed to work? The response that the CCC could do administrative work from home, and remotely, conflicts with the hands-on role expected of the CCC. The Defendant has been distracted by the idea that "office space" is not generally considered appropriate as part of the health service as a facility for meeting the care needs of an individual (see 2006 Act s.3(1)(i)). The true question is whether the Claimant's home is insufficient space for the delivery of the services to meet her needs, in which case the Defendant has a duty to fund more space. Ms Lowe identifies the correct question in her witness statement evidence: whether the office space is reasonably required to meet an assessed health and care need. But the Defendant's negative answer to that question is unreasonable. The Claimant stands to lose provision which is already evidenced as necessary for the carer arrangements, and for her physical and mental health and wellbeing and that of her carers. The Defendant has not grappled with any of this and has reached a decision beyond the range of reasonable responses.

28. I have been unable to accept these submissions. I have described the evidence about the office space. In an email dated 19.11.23, which was in the materials relied on by the Claimant's solicitor on 6.3.24, the Claimant also makes points about the office space. I have read and considered all of the points. I record here that they include this:

> ***The use of the office space has helped manage boundaries for me. We use the space for team meetings. Conducting interviews. Training (when we all fit). HR issues - if I have to tell staff off or issue a warning it is difficult to do that from my bed. The carers go sometimes when they need time out of / break- there is a kitchen, showers. It's 40 seconds away. The calls that could cause are distress are taken there removing me from the conflict. Admin is based there.***

I accept that the Claimant's home is small and that the office space is a considerable advantage. The decision letter emphasises that the office space "is not approved" adding that it does not feature in any iteration of the Claimant's care and support plan. I am unable to characterise as unreasonable – as understood in public law – the Defendant's failure or refusal to accept that the Claimant's home is an insufficient space for the delivery of the services to meet her needs, such that the Defendant has the responsibility to pay for a further room; still less any failure or refusal to accept that this is accommodation appropriate as part of the health service. The CCC's job description does not require full-time presence in the Claimant's home. There is no unreasonableness or illogicality in Ms Lowe identifying some tasks as capable of being performed from home or remotely. The Defendant has identified what is accepted as being the right question:

whether the office space is reasonably required to meet an assessed health and care need. It has in my judgment answered that question reasonably. I am unable to see any unlawfulness in the Defendant's approach to the office space. I accept the submissions of Mr Parkhill on this third part of the case.

Massage Therapy

29. I turn to the fourth topic. Mr Burton KC and Mr Baldwin submitted as follows. In the Claimant's previous care plan there was provision of £64 per week for massage therapy. To put this into context, the materials put forward by the Claimant's solicitor on 6.3.24 included an email chain from 16.2.23 about palliative care and the Claimant having unsuccessfully tried 7 pain clinics. Ms Lowe's witness statement evidence recognises that the Claimant has expressed the view that massage helps with her pain. The Defendant's reasoning in the decision letter says that "Dermatology advised against massages". Ms Lowe has pointed to a letter dated 3.10.23 from the Dermatology Consultant to the GP saying that massaging between the fingers "predisposes to injury", "may cause tenderness" and "is probably not helping her condition". But none of that engages with the pain relief advantages of massage therapy. It was unreasonable to put the Claimant's experienced benefit of massage therapy to one side. There was a failure of adequate enquiry in not reverting to the Claimant, in relation to an aspect of care previously funded and not identified as under consideration for withdrawal, to weigh up the pain relief advantages against the Dermatologist's observations. And it is illogical for Ms Lowe now to say in witness statement evidence that there could be flexibility in the use of the financial envelope for massages, since that could only come at a cost in respect of some other identified need. The previously unheralded exclusion of massage therapy is beyond the range of reasonable responses, or involved a failure of reasonable enquiry, or involved an illogicality in the reasoning process.

30. I am unable to accept these submissions. As the decision letter explained, massage therapy was not identified as reasonably required to meet an assessed health and care need. The Claimant knew that there was a fresh assessment of needs and provision and was able to put forward what provision she required and why. There is no 'minded-to' stage in these needs assessments. The decision letter was responding to what had been requested, having assessed the position. The Defendant acted lawfully in considering what the consultant Dermatologist had told the GP. In her witness statement evidence of 19.4.24 the Claimant adduced a histopathology report to indicate "why I need massage therapy" namely "to alleviate painful swelling". The exhibit is a letter of 9.9.20 from a dermatologist regarding swelling around the abdomen and legs. The point about pain relief has been considered and there is a response in the witness statement evidence. It is that the Defendant maintains that massage therapy is not reasonably required to meet an assessed need. That means there is no illogicality in declining to increase the financial envelope. I am unable to see any unlawfulness in the Defendant's approach to massage therapy. I accept the submissions of Mr Parkhill on this fourth part of the case.

Slidesheets

31. That takes me to the fifth topic in the case. Mr Burton KC and Mr Baldwin submitted as follows. The Defendant accepts that the Claimant has a need, which requires to be met, for slidesheets. The Plan expressly acknowledges, for "repositioning in bed", that "slide sheets [are] required to enable repositioning with [the] assistance of two staff". But slidesheets are not within the costed list of disposables (masks, wipes, aprons etc) in the

Plan. The Plan records that, should the Claimant need these, she would contact a given phone number or email address. However, the Defendant knew from the materials put forward by the Claimant's solicitor on 6.3.24 that this course had been tried and had failed. At an appointment on 10.5.23 the occupational therapist "explained and apologised that the incorrect size slide sheets have been delivered" and the Claimant had "stated she will purchase these privately as does not want to risk further errors being made, delaying her access to required equipment". A reasonable, person-centred approach would have recognised this. The Defendant's PHB Policy recognises at §6.13.13 that "case-by case" exceptions are appropriate in respect of equipment already commissioned by an ICB, and this was required as a reasonable exception. Further, the Claimant could and cannot reasonably be expected to make a referral for slidesheets until after the new CCC is in place. And Ms Lowe's witness statement observation about allowing the "urgent" and "exceptional" funding of slidesheets "within" the financial envelope is illogical, since the budget is allocated to cover other needs.

32. I am unable to accept these submissions. It was not beyond the range of reasonable responses for the Defendant to decide that slidesheets – like splints, hoisting aids and other equipment required to help the Claimant to mobilise and transfer – was available through occupational therapy services; and that this was the appropriate route notwithstanding the mistake acknowledged by the OT on 10.5.23. There was, and is, no evidence that anyone – including a carer or the PA – has made any phone call or sent any email, or raised this with occupational therapy. There was, and is, no evidence that this could not be done; nor that a referral now needs to await the appointment of the new CCC. I am unable to see any unlawfulness in the Defendant's approach to slidesheets. I accept the submissions of Mr Parkhill on this fifth part of the case.

Wheelchair

33. This is the sixth topic. Mr Burton KC and Mr Baldwin submitted as follows. The Defendant accepts that the Claimant has a need, which requires to be met, for a wheelchair. The Claimant has sourced a suitable electric wheelchair at £144 per week. It is vital to her mobility. The decision letter gives the reasons why this has not been included in the Plan. They are that "wheelchair funding is through NHS wheelchair services" and "the Claimant can request a referral at any time". But there are, on the evidence, three distinct problems with this:

    (1) The first problem is that the alternative route is tried, tested and has failed. The Claimant's solicitors had explained the position in an email on 25.3.24 (attaching a complaint letter dated 30.8.22):

> ***Wheelchair – We are informed that our client has never declined a referral for NHS wheelchair services – see complaint letter attached. As acknowledged in the ICB's Letter of Response, Ms Simpson was seen by wheelchair services but did not meet their criteria for an electric wheelchair on the basis that she had recurrent strokes. The wheelchair offered to her – which was unsuitable for her needs – was declined. Our client considered this was a blanket policy (as it failed to take into account her specific circumstances) and was unlawfully discriminatory on the grounds of her severe disabilities. She was then discharged from wheelchair services, and the ICB initially refused to fund the wheelchair within her PHB. However, an 8-week hire agreement was funded by the ICB until an alternative had been sorted. In light of her discharge from NHS wheelchair services, that never materialised; hence, from our client's perspective, the ICB's agreement to fund her wheelchair remains live.***

That means a case-by-case exception is reasonably needed, as described in the Defendant's PHB Policy at §6.13.13.

(2) The second problem is that the Defendant's insistence on funding a wheelchair only through the NHS referral route is linked to an exaggerated point about safety. The Defendant has relied on an email dated 26.9.22 from the LTCC Senior Manager Sue Patterson to Ms Lowe, which says:

> ***Looking at some of DS medical diagnoses we would also have concerns long term is there is further cognitive deterioration as to whether DS could manage a powered chair. Also for [noting] should DS have any seizures the powered chair would no longer be able to be left with DS for her own and others safety. This is the same practice as with a driving licence.***

This was a description of a possible future problem, if there were a further cognitive deterioration; it does not inform a present adverse decision.

(3) The third problem is about delay and interim arrangements. Any referral clearly needs to await the new CCC being in post. Whenever a referral were made, it is known to take considerable time. That means there needs to be an interim arrangement. But what would it be? This has gone entirely unanswered. In the email on 25.3.24 the Claimant's solicitors said this:

> ***In any event, if our client were re-referred to wheelchair services, this would likely be a protracted process – it previously took 18 months. Nor would there be any interim provision pending resolution; please confirm whether the ICB can propose any viable alternatives?***

In an email on 31.7.24 Ms Duggan asked:

> ***please could you confirm what the "proposed interim arrangements" to address the delay would look like in practice?***

These straightforward requests went unanswered. It was unreasonable for the Defendant not to identify an interim arrangement, which would be in place upon a referral being made. For this and the other reasons, the Defendant's response in excluding the wheelchair from the Plan and budget is outside the range of reasonable responses and unlawful.

34. I have been unable to accept these submissions. The Plan on 12.4.24 recorded that the Claimant "has acquired her own electric wheelchair outside of NHS provision" and "can request a wheelchair referral for an NHS funded wheelchair via her GP" with a phone number and website where "further information on the wheelchair service can be found". This had been raised in September 2023. In a letter on 6.6.24 Ms Lowe wrote:

> ***Interim arrangements for meeting your wheelchair needs, insofar as they are required, can of course be explored with NHS wheelchair services following referral.***

No referral was made, and no exploration of interim arrangements with NHS wheelchair services, "following referral", arose. There was and is no evidence that a referral would need to await a new CCC, or why that would be the case. This case would be different in its complexion if: (a) a referral had been made; (b) no suitable interim arrangement was available from NHS wheelchair services; (c) the Defendant had been requested to extend the Plan to fund the existing wheelchair; and (d) it had refused to do so. But that is not

the position. It was not beyond the range of reasonable responses for the Defendant to decide that a wheelchair was available through NHS wheelchair services, and that interim post-referral provision should first be explored with NHS wheelchair services, notwithstanding the events of 2022. The relevance of the safety point is this. It illustrates the sorts of issue which it would be for NHS wheelchair services to address – itself acting lawfully, reasonably and fairly – as the public authority specialist arm dealing with wheelchairs. I am unable to see any unlawfulness in the Defendant's approach to the wheelchair. I accept the submissions of Mr Parkhill on this sixth part of the case.

Travel and Hotel Costs

35. This is the seventh and final topic. Mr Burton KC and Mr Baldwin submitted as follows.

(1) It is self-evident that the Claimant has an assessed need to travel to her medical appointments. The CCC's job description requires the CCC to travel with her to them too. The decision letter of 12.4.24 refuses the requests for transport costs and hotel stays, on the basis that they were not identified as reasonably required to meet an assessed health and care need within the CHC package of care. That decision is beyond the range of reasonable responses.

(2) Funding had previously been allowed. On 9.11.23 it was described as £400 per month transport (based on taxis to The Royal Brompton and for London appointments) and £400 per month hotels (based on twice-monthly stays in Bristol). On 22.9.23 it had been recorded as £400 per week for transport and £200 per week hotels. This is a clearly evidenced need. In an email dated 25.1.24, provided by her solicitor on 6.3.24, the Claimant identified the different hospitals she has to attend and their locations, and describing the arrangements for stays in hotels. Also before the decision-makers was the GP's letter of 18.10.23 describing the 17 clinical appointments which the Claimant had attended in 30 days. This funding was simply removed.

(3) There is no reasoning in the decision documents. There was no enquiry, exploring with the Claimant alternative sources of funding and the lived experience of trying to access them. Ms Lowe's witness statement describes making contact with Ms Duggan in relation to information gaps, but not in relation to travel and hotel costs. The only explanation Ms Lowe gives is this:

> ***Ms Simpson is in receipt of benefits and owns a Motability vehicle which she can use to travel to appointments. She is funded for 2:1 support 24 hours a day and has a private electric wheelchair. There is no basis for a reasonable requirement for additional funding for transport costs to attend hospital appointments as this can be met through her personal finances and other benefits. At paragraph 46 of her witness statement of 19 April 2024, Ms Simpson has rightly identified that she has access to NHS funding for transport for appointments too. This is in the form of travel costs being reimbursed via the low-income funding scheme and also via hospital transport (though this appears not to have worked well for her in some cases). These schemes are not managed by the ICB and are properly the responsibility of the Trusts providing Ms Simpson's care and treatment.***

(4) The problem with this reliance on alternatives is that they do not cover the transport costs. So far as benefits are concerned, the Claimant's third witness statement (31.10.24):

> ***I am continuing to pay for my transport expenses out of my disability benefits, which includes PIP enhanced mobility component at a rate of £75.15 per week; however, this money is earmarked towards my Motability vehicle. It does not cover the additional costs of petrol.***

So, this leaves the petrol costs entirely unfunded.

(5) Ms Lowe acknowledges that the hospital transport scheme have "not worked" for the Claimant. The Claimant's first witness statement (19.4.24) was clear and explicit:

> ***I am getting pushed further and further into poverty due to these restrictions. I am entitled to hospital transport. So, there is the 'low income scheme' on the NHS which reimburses travel fares; but the issue I have is that you have to pay out for the travel fare before you are reimbursed. You wait sometimes 90 minutes at these cashier desks having to evidence need – I am simply not well enough. I need the ICB to realise that this is my day-to-day reality…***

(6) The Defendant has failed to act reasonably. It did not undertake a reasonable enquiry. It has not appreciated that PIP enhanced mobility component is swallowed up by costs relating to the mobility vehicle, and does not cover any petrol. It has failed to appreciate that the NHS reimbursement schemes do not in practice work for the Claimant at all. The exclusion of transport costs, and hotel costs, is not a reasonable response.

36. I have been unable to accept these submissions. The position as to hotels is that the Defendant did not consider these to be reasonably required to meet an assessed health and care need within the CHC package of care. It is in my judgment impossible to characterise that evaluative decision as unreasonable as to outcome or enquiry. Transport gives rise to different considerations. It is self-evidently a need requiring to be met. Unlike the position with slidesheets and wheelchairs, and notwithstanding §6.13.14 of the Defendant's PHB Policy, the Plan did not refer to the NHS reimbursement schemes. However, the Claimant's first witness statement (19.4.24) referred to her disability benefits and said PIP "does not even touch the sides of how much it would cost to get me to and from these hospital appointments". Ms Lowe's response (13.5.24) recorded the Defendant's position, that travel costs were covered by disability benefits with the safety net of NHS schemes, notwithstanding difficulties "sometimes" (as the Claimant put it). Insofar as the Claimant's post-decision witness statement is relevant evidence of what an enquiry would have elicited, it does not in my judgment undermine the reasonableness of the Defendant's position. The Claimant's evidence indicates at least partial success, albeit as a reimbursement and "sometimes" with a very long wait.

37. The Claimant has very recently (31.10.24) described her PIP (£75.15 per week) as "earmarked towards my Motability vehicle" and has said that there is "nothing left for petrol". In that statement, she has not provided any further detail or update as to NHS reimbursement of petrol money and the ongoing experience of trying to access it. But she has, very properly, given me a good practical picture of the scale of the problem. She identifies her 6 petrol payments totalling £497.03 over 9 months, as follows:

> ***6 December 2023 - £62.00 petrol***
> ***8 December 2023 – Great Ormond Street Hospital – 55 mile return journey***
> ***2 January 2024 – Brompton hospital – 66 mile return journey***
> ***9 January 2024 – GP surgery in Brentwood – 2 mile return journey***

22 January 2024 – Harold Wood clinic – 10 mile return journey

5 February 2024 - £67.77 petrol
12 February 2024 – Harold Wood clinic – 10 mile return journey
22 February 2024 – Hutton (dentist) – 7 mile return journey
4 April 2024 – Addenbrookes hospital – 98 mile return journey
8 April 2024 – Harold Wood clinic – 10 mile return journey
18 April 2024 – Brompton hospital – 66 mile return journey
19 April 2024 – National neurological hospital – 60 mile return journey

30 April 2024 - £95.01 petrol
8 May 2024 – National neurological hospital – 60 mile return journey
14 May 2024 – Brentwood community hospital – 3 mile return journey
20 May 2024 – Brompton hospital – 66 mile return journey
13 May 2024 – Basildon hospital – 22 mile return journey

13 June 2024 - £94.77 petrol
19 June 2024 – Brompton hospital – 66 mile return journey
21 June 2024 – Hutton (dentist) – 7 mile return journey
24 June 2024 – Moorfields hospital – 52 mile return journey

30 June 2024 - £86.05 petrol
8 July 2024 – Brompton hospital – 66 mile return journey
11 July 2024 – Addenbrookes – 98 mile return journey
18 July 2024 – Brompton hospital – 66 mile return journey

29 August 2024 - £91.43 petrol
31 August 2024 – National Neurological hospital – 60 mile return journey
5 September 2024 – Guys hospital – 58 mile return journey
10 October 2024 – Guys hospital – 58 mile return journey

38. I make the following observations. This £497.03 over 9 months is very different in scale from the 9.11.23 description of £400 per month for transport costs and the 22.9.23 reference to £400 per week. The petrol costs of £497.03 over 9 months will have arisen alongside what would have been some £2,900 in PIP payments (at £75.15 per week). It would be open to the Claimant to provide a fully documented picture about the PIP payments and how they are "earmarked" for the Motability vehicle and cover no petrol; and about what the ongoing position has been regarding attempts to obtain reimbursement. I note that Ms Lowe responded to the latest witness statement, by identifying a needs review in the context of information about worsening needs. If benefits do not cover petrol, and if NHS reimbursement is inaccessible, this would seem to fall squarely within the review which Ms Lowe describes. Some flexibility in the Plan and funding could be called for. And that could involve an expansion of the financial envelope. But these are matters for the Defendant to consider, if further evidence is provided to it.

39. Returning to the impugned decision, I am unable to see any unlawfulness in the Defendant's approach to hotels and transport. I accept the submissions of Mr Parkhill on this final part of the case.

Conclusion

40. In conclusion, the Defendant's evaluative judgments as the primary decision-making authority are lawful, when tested against standards of reasonableness review. Notwithstanding an intensity of review which is high and a scrutiny which is close, this case still lies squarely in the area where I must respect the functional distance between

primary decision-maker and secondary reviewing court. I will grant permission for judicial review, because the modest threshold of arguability was crossed. But, on analysis of the facts and circumstances, the claim for judicial review fails and I must dismiss it.

Order

41. Having circulated this judgment in draft, I am able to deal here with consequential matters. The parties were agreed that the appropriate Order, in light of what I have decided, should be as follows. (1) The Claimant's application for permission for judicial review is granted. (2) The Claimant's claim for judicial review is dismissed. (3) The Claimant shall pay the Defendant's costs, with the sum payable to be determined upon any application under regulation 16 of the Civil Legal Aid (Costs) Regulations 2013. (4) There shall be a detailed assessment of the Claimant's publicly funded costs.

Permission to appeal

42. Mr Burton KC and Mr Baldwin sought permission to appeal on three grounds. First, that this Judgment does not provide adequate or sufficient reasoning, in particular at §§21, 23, 26, 30, 32, 34 and 37. Secondly, that on the lawfulness of the response to office space the Judgment is wrong in law and erroneous on the evidence. Thirdly, that on lawfulness of the response to travel and hotel costs the Judgment is wrong in law and erroneous on the evidence. Since I have been unable to see a real prospect of success, absent which there is in my judgment no compelling reason for an appeal to be heard, I refuse permission to appeal.