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2009 No. 123561-01

IN THE HIGH COURT OF JUSTICE IN NORTHERN IRELAND

QUEEN'S BENCH DIVISION (JUDICIAL REVIEW)

PF and JF's Application [2011] NIQB 20

IN THE MATTER OF AN APPLICATION BY PF BY HIS BROTHER AND NEXT FRIEND JF FOR JUDICIAL REVIEW

and

IN THE MATTER OF DECISIONS OF THE SOUTHERN EASTERN HEALTH AND SOCIAL CARE TRUST

GIRVAN LJ

Introduction

[1] This judicial review application brought by PF, a person under disability, by his brother and next friend JF, seeks to challenge decisions made by the South Eastern Health and Social Care Trust ("the SE Trust") in relation to the level of direct payments for care being provided to him. It is an application which raises a number of important questions under the Carers and Direct Payments Act (Northern Ireland) 2002 ("the 2002 Act"), the Personal Social Services and Children's Services (Direct Payments) Regulations (Northern Ireland) 2004 ("the 2004 Regulations"), the Chronically Sick and Disabled Persons Northern Ireland Act 1978 ("the 1978 Act") and the Health and Personal Social Services (Northern Ireland) Order 1972.

[2] The case presented by the applicant is that the level and amount of direct payment for care being provided to the applicant by JF was unlawful and in breach of the applicant's rights under Article 8 of the Convention and in breach of the United Nations Convention on the Rights of Persons under Disabilities ("the UN Convention"). The applicant seeks an order of certiorari quashing the decisions of the Trust not to provide the level or amount of direct payment for care and provision

of care, in accordance with the assessed needs of the applicant. He seeks an order compelling the Trust to provide direct payments or provide for care on the basis of the applicant's assessed needs being a need for 24 hour care and supervision. He challenges the refusal of the Trust to backdate a 21 hour increase in the amount of direct payment of care in accordance with the assessed needs of the applicant as previously determined and seeks an order to compel the Trust to backdate the payment to 1 October 2007, being around the date of the conclusion of care assessments on which the relevant authority must have relied in its decision of 5 February 2009 to allow the additional 21 hours. Alternatively he seeks damages to the same effect under the Human Rights Act 1998.

[3] At the outset to the hearing the court raised the question whether it was entirely appropriate that PF was bringing the application by his brother JF as next friend, since JF might have a financial interest of his own to further and protect in the proceedings. At the heart of the present issues between the F family and SE Trust lies the proposition that JF and his partner are not receiving just recompense for the very high level of care provided by them to PF who is severely disabled. The unfolding and developing argument as it proceeded did demonstrate that the application, in its original form, failed to appreciate this aspect of the case. As the case proceeded, it became increasingly clear that the statutory basis relied on by the SE Trust for payments in respect of PF's care was legally flawed for reasons set out later in this judgment. This conclusion obviously affects the question what relief, if any, should be granted in the case.

The factual context

[4] PF suffers from severe learning disability and a large range of disabilities. It is believed that these are attributable to his contracting meningitis at the age of 6 months. He is doubly incontinent. He suffers episodes which have been considered as possible seizures. He may be suffering from epilepsy. He has been diagnosed with autism though that diagnosis has been brought into doubt. He has a long history of behavioural problems, including temper tantrums, the eating and drinking of inappropriate materials, a total lack or concern or regard for his own safety, sleep disturbance and self harm. In what is described as an interim psychological report by a consultant clinical psychologist, Dr Irvine, dated 30 September 2003 it was her assessment of PF's attained age equivalent of developmental levels that his highest age equivalent developmental level was 2 years 6 months for fine motor skills. The lowest is for coping skills, play and leisure time skills and expressive language where his equivalent age is 11 months. He is reticent to engage with unfamiliar people although over time he can develop relationships and bonds.

[5] PF was cared for by his mother and father until some 15 years ago. His father died in 2002 and his mother in 2008. The applicant's brother JF was very involved in his care even when the applicant lived with his parents. PF also attended day care.

[6] The applicant went to live with JF in Leeds some 15 years ago. He attended day care but the day care centre raised concerns about his behaviour. Not long after he came to live with his brother, his brother gave up work and cared for the applicant full time with the assistance of his former partner. After 4 years in Leeds, JF and his partner split up and JF returned to Northern Ireland with PF in March 2002. Initially they lived in the Beechgrove area of Belfast.

[7] In the period when PF lived with his brother in Belfast his care fell within the jurisdiction of the South and East Belfast Trust ("the Belfast Trust"). It was suggested to JF that a direct payment would be the most suitable means of providing support and an application was made to the Belfast Trust. JF's understanding was that the Belfast Trust considered the applicant required 24 hour supervision. It was explained to JF by the care co-ordinator that if the Trust provided £200 worth of Trust services per week, then the threshold for the Independent Living Fund ("ILF") would be reached. An application was made to ILF. As a result direct payments were received from the Belfast Trust of £212 per week (equivalent to 28 hours at £7.60 per hour and £375 per week from ILF based on 43 hours plus 9.5 hours for cover of one night per week.

[8] In or about August 2003, JF and PF moved into a house in Regency Square in Bangor and then moved to 41 Hanover Chase, Bangor, where the brother's partner resided. This was within the area covered by the SE Trust. The brother and his partner now have 2 children of their own, aged 6 and 3.

[9] It is JF's case that he provides 24 round-the-clock care of the applicant. The applicant's sleeping pattern is erratic and he can get up during the night and thus JF and his partner always need to be available to deal with emergencies. Accordingly, JF maintains, PF requires constant care and attention 24 hours, 7 days a week.

[10] When JF moved to Bangor in late August 2003 he was informed by the Ulster Community and Hospitals Trust (now the SE Trust) that it could not sustain the same level of care by direct payments as the Belfast Trust had made. Direct payments did not resume until 12 December 2003 and for a period the same level of payments as had previously been made by the Belfast Trust was provided.

[11] In a document described as a direct payment scheme arrangement dated 4 December 2003, purporting to be made between "PF (care of JF)" and the SE Trust's predecessor, the Trust agreed to provide a sum of money to enable PF to make his own support arrangements, including employing and managing his own personal care assistants. The amount of money would be based on PF's need for assistance as detailed in his assessment and in keeping with the criteria of support at home. The amount of money would be calculated on an average weekly sum basis for a monthly period, payable monthly, in advance. The basic hourly rate shown in the statement included allowances for employer's national insurance contributions, holiday pay and public liability enhancement. The Trust would appoint a key worker who would review PF's requirements with PF after 6 weeks, 3 months and

every 6 months thereafter. The contract contained quite complex terms imposing, for example, a duty to comply with Equality Opportunity legislation, financial accountability requirements and insurance requirements. Bearing in mind that PF could have no understanding of the agreement and no capacity to contract there was in fact no legal basis for the arrangements purportedly entered into on the terms fixed by the Trust.

[12] For a period, as a result of a view taken by the ILF, it withdrew funding because JF was living in the same house as PF. This surprising decision, according to JF, was supposed to be based on a policy that care provided by a live-in relative would not be funded. As a result JF was forced to live away from the house for a period. On 1 April 2006, direct payment was suspended and withdrawn leading to cessation of ILF funding, which was dependent on Trust funding. This was apparently because the Trust was not satisfied with the paperwork being provided by JF. The cessation of funding led to severe financial difficulties for JF and resulted in a claim for possession of his dwelling house for non-payment of mortgage instalments.

[13] Following the cessation of payments for a period of time the Trust reinstated payments in mid-August 2006. It allocated 35 hours per week in lieu day care and 6 hours for respite (i.e. a total of 41 hours) the reinstatement occurred following a meeting on 2 August 2006. The Trust also allowed an allowance of £113 per week for laundry services.

[14] A direct payment scheme was entered into on 15 August 2006. This purported to be in agreement between PF and the Trust in respect of services for PF, JF and GC (JF's partner), described as "the service user". It was in somewhat different format from the agreement purportedly made in December 2003, it was signed by JF under whose name appeared the words "appointee/agent". Under "capacity" appear the delphic initials 'NOK'. Appendix C indicated the details of assessed hours were 54 at £8.27 per hour. There was nothing in respect of night sleepovers. The weekly cost was described as £451.30.

[15] Following a meeting at Marine Court Hotel, Bangor, between representatives of the Trust and JF and his partner on 15 March 2007, it was agreed that there would be a new assessment on the applicant's needs and care requirements. As a result a social work assessment and care assessment was undertaken on 22 March 2007. The care plan stated that the applicant required 24 hour care, support and supervision. The action plan attached indicated the need for a support package to maintain PF in his own home through supported living. Other assessments carried out around that time highlighted profound disabilities in respect of attention and listening skills, the need for full assistance with personal care and intimate hygiene in view of his ongoing incontinence, profound eating problems with the need for extreme care in food preparation and feeding and his autistic symptoms requiring a clear routine and predictability.

[16] On 5 February 2009, Ms Hamill became the responsible care manager. She stated that she could offer a further 21 hours for personal care and assistance with meals. This thus brought the total number of hours of care provided for by direct payment to 62 hours per week. However, there was no back-dating of the additional 21 hours to the date of the 2007 assessment.

[17] JF complained that this additional allowance was inadequate to meet the true cost of the care package he and his partner, GC, were providing. He sought to appeal the decision. By letter of 12 August 2009, the Trust confirmed the decision and indicated that the weekly payments now amounted to £663.54 per week. In further correspondence, the Trust, through its legal services department, stated that the reasons for the decision were a reassessment of the applicant's needs and a formal assessment carried out between 24 and 26 June 2009 confirmed the Trust's decision.

[18] The June 2009 assessments took place at Sunnyside Cottage in Bangor. JF objects to the adequacy of those assessments and complains he received no details of events involved in the care of PF during night cover. He contends that relevant adverse and dangerous events which had occurred highlighting the need for extreme care in his care and supervision were not properly recorded. It is his case that all the evidence points to a need for 24 hour care and supervision.

[19] Ms Hamill, who is described as the Sector Manager of Adult Learning Disability Services employed by the SE Trust and who has been involved in decision-making in respect of the applicant made a number of points in her first affidavit:

> (a) The direct payment scheme was set up to enable carers (sic) to purchase services identified by the Trust as necessary for the care of PF. It is not to be used for residential care (care requiring 24 hours a day, 7 days a week). It is for JF to assist PF in the purchase of the services.
>
> (b) Relatives persons living with the service user should not be used to provide services unless there were exceptional circumstances.
>
> (c) The Trust did not accept that PF required 24 hour care or constant observation. The element of actual care was substantially less than the need for supervision (i.e. an adult being available should PF require him).
>
> (d) The Trust would welcome a residential assessment of PF to assess his needs day and night.
>
> (e) There are suitable facilities available to provide residential care.
>
> (f) PF and his carers were receiving financial assistance out of state benefits payable to PF and they could assist in the purchase of care and assist

in transportation. It could not be correct that the applicant should have direct payments for care for 24 hours a day since there would be an element of duplication on payment (see paragraph 12 of her first affidavit).

(g) The direct payment scheme operates on a contractual basis, payments being made directly to PF who can then purchase the identified services for himself.

(h) There should have been quarterly returns made and timesheets and receipts furnished to vouch expenditure. These had not been provided to the Trust.

(i) As part of the direct payments scheme consideration could also be given to the carer's situation. The decision to increase the direct payment by 21 hours reflected JF's position that he could not take up employment due to his decision to care for his brother on a full-time basis.

(j) The cessation of direct payments occurred because of JF's failure to provide the documentation required in accordance with the scheme.

(k) The Trust had provided some goodwill payment to enhance the working relationship with JF.

(l) The increase of 21 hours was based on professional judgment and not on an up-dated assessment. It was influenced by the distress of the carers, evidence of increased need for incontinence pads, a better knowledge regarding the time allocated to personal care and in an effort to be reasonable, proportionate and helpful. Ms Hamill made the point that if able-bodied carers are in the home the Trust would not routinely help. It did not routinely put in help to assist with personal care unless the help of two and/or equipment was required or unless a client was living on his own. The factors to which the SE Trust had responded in this instance was "the carer request for support to reduce stress."

(m) There was no provision for back-dating payments. The scheme envisaged a contract for services payment being made 4 weeks in advance.

(n) The Trust accepted that PF had particular needs which meant he could not live on his own and required 24 hour care and supervision but not 24 hours constant care.

(o) The behaviour support assessment and carer's assessment did not make any statements regarding the need for 24 hour home care.

(p) PF could not live on his own due to his severe learning disability. Thus he must live either within the context of the family home or within the context

of residential accommodation. The current cost of residential care would be £426 (nursing home care would be £537 per week). PF is actually receiving £676.54 per week. The Trust is content to directly provide the services required and to withdraw direct payments thereby enabling JF and GC more time to themselves and their family.

(q) Kathy Kirby, who JF relied on as a nursing expert, did not even support a case for 24 hour care 7 days a week and her assessment was 98 hours.

(r) If PF were allowed to engage with day care services he could c ope and would derive positive benefit from social interaction with his peers that would be in PF's best interests.

[20] Ms Hamill swore a third affidavit on 11 February 2011 shortly before the hearing of the application. In it she referred to a policy circular dated 3 June 1999 the Circular HSC (ECCU) 1-2010 issued by the Department on 11 March 2010. The state benefits were not to be used to buy care and by inference were not to be taken into account when considering care needs and the assessment of what the Trust believed was necessary to meet the needs of an individual. She deposed that in all assessments that she carried out during her involvement with the applicant and his carers, the issue of benefits had not featured. This appears to contradict the contents of paragraph [30] and paragraph [41] of her first affidavit. She said that in reality at no stage during her assessment of what direct payments were required did she consider that he should purchase additional care for himself.

[21] In paragraphs [6] and [7] of the affidavit Ms Hamill stated:

> "(6) It was, however, a relevant consideration that the applicant was living with his family and that having regard to the resources available to the Trust, there would be reliance by the Trust on the informal caring arrangements and supervision which someone, even with the applicant's disability, would receive from family members.
>
> (7) In the applicant's case care was assessed at 35 hours per week in lieu of day care because it was accepted by the Trust that the applicant's carers would provide daily care in lieu of normal day care provision (7 hours a day 5 days a week). In addition 21 hours per week for personal care and assistance with meals and 6 hours per week for carers respite. Although it was accepted that the applicant required constant supervision, it was regarded as necessary for the Trust to essentially pay family members for that supervision."

[22] Ms Hamill went on in paragraph [8] of her affidavit to state that the payment to family members for the purchase of direct care was not envisaged as being normal means by which care could be purchased although it could be allowed in exceptional circumstances as in this case. If the Trust became obliged in every case where constant supervision was required to pay for that supervision then it would lead to a greater emphasis on providing long-term residential care because of cost savings.

The Parties' Submissions

The Applicant's Case

[23] Mr Dingemans QC who appeared with Dr Sharpe submitted that at the heart of the applicant's case was the premise that providing 62 hours care a week to the applicant as opposed to 24 hours care per day which was actually required constituted a breach by the SE Trust of its legal duty under the 2002 Act and the 2004 Regulations. PF required full care when he was awake and some care and always supervision at night. The decision made on 5 February 2009 on a request for reconsideration of the direct payments in light of the assessed needs and the appraisal led to an additional 21 hours of direct payment per week allowed for personal care and assistance with meals. That decision while welcome was not based on any new information and no objective criteria were used. The Trust's approach, it was argued, could only have been based on the SE Trust's view that because the carers are members of the family of the applicant then they cannot and should not receive payment for all hours of care needed. The failure to adequately assess the applicant's needs and to award direct payments at a level which was less than the applicant's assessed needs engaged Article 8 of the Convention.

[24] Counsel further argued that the Trust erroneously considered that making payments on a 24 hour-7 day basis to the applicants would amount to paying for residential care which the Trust argued was not permitted under Regulation 8. This was an erroneous interpretation of Regulation 8 the purpose of which was to prevent long-term residential home care being funded by direct payments rather than by alternative procedures which are in place for the funding of such care. Furthermore the Trust erroneously took into account the applicant's benefits in relation to severe Disablement Living Allowance, Income Support, high Care Component and high Mobility Allowance. These the Trust treated as means which would lead to reduction in the provision of direct payments for carers. They were in fact benefits paid to reflect additional living costs associated with disability.

[25] It was part of the applicant's case that the Trust had no rational basis for its refusal to backdate the extra hours awarded in February 2009. None of the carers' alleged failures in respect of the paperwork excused the Trust from its own duties.

[26] The approach adopted by the Trust breached Article 8 of the Convention. The applicant's ability to remain with his family and receive care in their home

depended on the receipt of direct payment assessments with the applicant's assessed needs. A similar conclusion was produced by an analysis of the UN Convention which had been incorporated into EU law by the European Communities (Definition of Treaties) United Nations Convention on the Rights of Persons with Disabilities) Order 2009 ("the EC Order").

The Respondent's Case

[27] Mr Lockhart QC who appeared with Miss Sholdis on behalf of the SE Trust in his written skeleton argument argued that the Trust accepted that PF had assessed care needs which required the provision of care designed to meet his needs. These needs were currently being met by JF and GC. The Trust had taken into account all the assessment outcomes and the facts and circumstances of the case including the fact JF and GC were meeting some of his assessed needs. In lieu of the Trust directly providing the services for PF the Trust had made and continues to make provision for PF to receive direct payments to enable him, with the assistance of JF and GC, to purchase the services. The Trust had carried out its obligations under Section 1 of the 2002 Act. In his original skeleton argument counsel had asserted that the Trust was entitled to rely on the nature and extent of the state benefits payable to PF but in the light of Ms Hamill's most recent affidavit that argument was withdrawn. It was argued that the direct payments were properly paid and calculated under the 2004 Regulations. Direct payments were not intended to replace existing support networks within families and communities. Direct payments were intended to support independent living and could not and should not be used to pay for permanent residential accommodation. JF's claim to payment equivalent to 24 hours a day care would amount to a demand for payment to purchase residential care which is clearly prohibited by the legislation itself. Counsel called in aid LW's Application [2010] NIQB and JR30. The Trust had carried out assessments and in lieu of the provision of services had made direct payments to enable the applicants to purchase those services. The decision to fund a further 21 hours of direct payments was based on (a) the professional judgment of the Service Manager taking all relevant factors into account; (b) took account of evidence as to PF's need to be changed more frequently than earlier thought; and (c) took account of the distress of the carers and their request for support to relieve stress. The Trust was entitled to reject various aspects of Ms Kirby's assessment. PF's care was provided totally within the home and the Trust considered that some of his needs could be met out of the home in other settings which would provide him with stimulation and social integration. The Trust argued that its assessments were frustrated to some extent by the carers. The Trust had offered the following which had been refused:

(a) an opportunity to avail of some services;

(b) an opportunity to avail of respite care; and

(c) an opportunity to purchase services from other agencies.

The Trust had an obligation to ensure cost effectiveness. Direct payment must be as cost effective as it would otherwise provide. If the service can be secured to an acceptable quality by a cheaper method the Trust would not be obliged to provide the extra associated costs. It is also entitled to evidential vouching (which had not been provided by JF). PF had contracted for direct payments to be provided to enable him to purchase the support and services to meet the assessed needs of PF. JF was not entitled to seek payment for care that had not been contracted the applicant had no entitlement to back payment.

[28] In his oral submissions Mr Lockhart on instruction sought to argue that in fact notwithstanding appearances to the contrary in the original affidavit the Trust had not taken account of payments of state benefits to PF and have done so would have breached the Trust's own policy.

The relevant statutory provisions

[29] The Health and Social Care (Reform Act) (Northern Ireland) 2009 (which came into operation on 1 April 2009) in Section 2(1) provides that the Department shall promote in Northern Ireland an integrated system of health care and social care. The Department must determine priorities and objectives for the securing of the improvement of health and allocating financial resources having regard to the need to use such resources in the most economic and efficient and effective way. Article 15(1) of the 1972 Order (as amended) provides that:

> "In the exercise of its functions under Section 2(1)(b) of the 2009 Act the Department shall make available advice, guidance and assistance to such extent as it considers necessary and for that purpose shall make such arrangements and provide or secure provision of such facilities (including the provision or arranging for the provision of residential or other accommodation, home help and laundry facilities) as it considers suitable and adequate."

Under Article 15(1)(A):

> "Arrangements under paragraph (1) may include arrangements for the provision of any other body or person of any of the social care on such terms as may be agreed between the Department and that other body or person."

[30] Section 2 of the Chronically Sick and Disabled Persons (Northern Ireland) Act 1978 provides:

> "2. Where the Department of Health, Social Services and Public Safety for Northern Ireland is satisfied in the case of any person to whom Section 1 applies that it is necessary in order to meet the needs of that person for that Department to make arrangements under Article 4(b) and 15 of the Health and Personal Social Services (Northern Ireland) Order 1972 for all or any of the following matters namely –
>
> (a) the provision of practical assistance for that person in his home . . .
>
> (g) the provision of meals for that person whether in his home or elsewhere
>
> . . . then the Department shall make those arrangements."

Section 1 refers to persons substantially handicapped by illness, injury or congenital deformity and whose handicap is of a permanent or lasting nature or is suffering from mental disorder within the meaning of the Mental Health (Northern Ireland) Order 1986 and refers to the need for the making by the Department of arrangements for promoting social welfare of such persons under Articles 4(b) and 15 of the 1972 Order.

[31] The Carers and Direct Payments Act 2002 in Section 8 provides:

> (1) Regulations may make provision for and in connection with requiring or authorising an authority in the case of a person of prescribed description who falls within sub-section (2) to make, with that person's consent, such payments to him as the authority may determine in accordance with the regulations in respect of his securing the provision of the service mentioned in paragraph (a) or (b) of that sub-section.
>
> (2) A person falls within this sub-section if the authority has decided -
>
> (a) under the 1972 Order that his needs call for the provision by it of a particular personal social service . . ."

Sub-section 3 empowers the making of Regulations which may make provisions for specifying circumstances in which the authority is not required or authorised to make payments, for any payments required or authorised by the Regulations to be made to a person by the authority as gross payments or alternatively as net payments and authorising direct payments to be made to any prescribed person on behalf of the payee. Sub-section 6 provides:

> "Regulations made for the purposes of sub-section 3(a) may provide that direct payments shall not be made in

> respect of the provision of residential accommodation for any person for a period in excess of a prescribed period."

[32] The Personal Social Services and Children's Services (Direct Payment) Regulations (Northern Ireland) 2004 in Regulation 2 provide:

> "If the conditions in paragraph (3) are satisfied the authority must make in the case of a prescribed person who falls within Section 8(2) of the Act, with that person's consent, such payments to him (direct payments) as the authority may determine in accordance with Regulation 5 in respect of his securing the provision of a relevant service."

Regulation 3 provides that a person is of a prescribed description if:

> "(a) he is a person who appears to the authority to be capable of managing a direct payment by himself or with such assistance as may be available to him."

However that does exclude certain persons which include for example a person subject to guardianship under the 1986 Order. Under Regulation 5 the authority shall determine, having regard to the prescribed person's means, what amount, if any, it is reasonably practicable for him to pay towards securing of the relevant service whether by way of reimbursement or by way of contribution.

[33] The conditions in respect of direct payments are set out in Regulation 7 which provides:

> "A direct payment shall be subject to the condition that the service in respect of which it is made shall not be secured from a person specified in paragraph 2 unless in the case of a service mentioned in Regulation 2(2)(a) or (b) the authority is satisfied that securing the service from such a person is necessary to meet satisfactorily the prescribed person's need for that service."

The persons referred to in paragraph 1 are relatives and include a brother or sister. Thus prima facie a direct payment may not be made to pay a relative for the provision of services but it may be paid if the authority is satisfied that it is necessary to meet the prescribed person's need satisfactorily. Regulation 8 provides that the direct payment may not be made for the purchase of residential accommodation for a period in excess of 4 weeks in any 12 month period. Regulation 11 provides for termination of direct payments if a person ceases to be a prescribed person. Regulation 11(3) provides that notwithstanding that the person in respect of whom

direct payments are made ceases to be capable of managing such payments an authority may continue to make such payments if –

> "(a) The authority is reasonably satisfied that the person's incapability will be temporary.
>
> (b) Another person is prepared to accept and manage such payments on the incapable person's behalf.
>
> (c) The person with whom the arrangement for the provision of the relevant service has been made agrees to accept payment for the services from the person mentioned in sub paragraph (b)."

[34] The UN Convention in Article 19 provides that:

> "States parties to the present Convention recognised the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community including by ensuring that:
>
> (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
>
> (b) Persons with disabilities have access to in-home residential and other community support services including personal assistance necessary to support living and inclusion in the community and prevent isolation or segregation from the community;
>
> (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs."

The legislative provisions in the 1972 Order, the 2009 Act, the 2002 Act and the 1978 Act together with other legislation dealing with the rights of disabled persons represent the UK's attempt to fulfil the obligations undertaken by the UK under the Convention. Mr Dingemans argued, correctly, that the relevant legislation falls so far as possible to be construed compatibly with the undertakings of the UK under the Convention.

The need for consent issue

[35] The power to make a direct payment which is exercisable subject to compliance with the Regulations permits payment to the person requiring care (whom I shall call for ease of reference "the patient") so as to enable him to secure the provision of a particular personal social service called for by reason of his needs. It thus enables the patient to effectively buy in care. The payment can only be made "with that person's consent." The clear aim of the legislation is to recognise the personal autonomy of the patient and to ensure that he is a willing participant in a financial package between himself and the relevant authority which thus cannot purport to fulfil its statutory duty by simply making payments to the patient against his will. The power is not exercisable to buy in residential accommodation for a person in excess of a prescribed period (i.e. a period in excess of 4 weeks in any period of 12 months under Regulation 8(1). The limitation on the payment for residential care flows from the fact that there is a separate financial scheme relating to the funding of residential care. Since the payment can only be paid to the patient with his consent Section 8 necessarily presupposes a person with the mental capacity to consent.

[36] Mr Dingemans argued that the words "with that person's consent" require a purposive interpretation in the light of the UN Convention (incorporated into domestic law by the EC Order) and that Section 8 should be interpreted as enabling JF to exercise PF's powers to receive the monies under Regulation 8. There is, however, nothing in the Convention which supports or demands such an approach. Article 19 does require the state to recognise the right of persons with disabilities so far as possible to live in the community and have the opportunity to choose their place of residence with the right of access to a range of home support services. It recognises the personal autonomy of persons with disabilities. It does not deal with the question of legal capacity to enter into contractual arrangements. Section 8 of the 2002 Act envisages a contract between the patient and the authority whereby the authority provides funds to the patient to contract with others to buy in services or benefits to help him cope with his disabilities. The purported contracts entered into in the present instance purported to impose strict and complex terms on PF in relation to how he dealt with the direct payments. In reality the contracts were a legal fiction, something which counsel in the course of argument were bound to concede. The reality is that the Trust should have known that the payments were going directly to JF. They were in effect a form of recompense for JF and his partner in connection with the care they were clearly providing and providing effectively. The contracts were never really intended to operate as contracts between the patient and the Trust. The allegedly contractual but in fact fictional basis of the arrangements provided a false legal foundation for the payments made. That is not to say that the Trust would not have had another and proper legal basis for making such payments for the care of the patient.

[37] The legal fallacy in the arrangements was something which should have been obvious to the Trust. Indeed, from what Mr Lockhart said in submissions, it appears that the Trust has for some time been aware of a serious question mark hanging over

the purported legal basis for the direct payments arrangements. The problem arising from the consent requirement in Section 8 was one which had become clear to the relevant authorities in England where legislation was enacted to avoid the problem. Thus in England the Health and Social Care Act 2008 Section 146 and the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009 effectively avoided the problem to be found in Section 8 of the Northern Ireland Act. The English legislation amended Section 57 of the English 2002 Act (the equivalent provision of Section 8 in the 2001 Act). The new legislation permits payment to a suitable representative of a patient with disability depriving him of the power to consent. It is somewhat surprising that the Department in this jurisdiction was apparently unaware of the English amendment or the need to amend Section 8 to lay a proper legal basis for a direct payments scheme entered into directly with a carer in the case of a person under mental disability.

[38] Mr Dingemans argued that Regulation 3 permitted the SE Trust to enter into the agreements in question. Regulation 3 permits the payment to a person under disability because a person of a prescribed description is defined as including a person who appears to be capable of managing a direct payment by himself or "with such assistance as may be available". However Regulation 3 cannot override the effect of the wording of the primary legislation which requires consent. Regulation 3 must accordingly be interpreted as referring to physical or organisational assistance necessitated by physical rather than mental incapacity (which deprives a person of the ability to consent at all). Indeed, Regulation 11 deals with the situation of a temporary but transient loss of capacity. It makes clear that when a person ceases to be capable of managing such payments payment may continue on a temporary basis. It also presupposes in paragraphs (b) and (c) that the person providing the services paid for is different from the person who is prepared to accept and manage the payments on a temporary basis. This recognises the undesirability of the carer and the manager of the direct payment fund being one and the same person for it is not difficult to foresee the possibility of a conflict of interest arising between the interests of the patient and the paid carer, a point which takes us back to the procedural difficulty the court raised with the parties at the outset of the case.

[39] Since there was no underlying legal basis for a direct payment scheme in relation of PF who had no mental capacity the Trust's decision for that reason cannot stand. The Trust must reconsider the position in the light of the fact that any funding of care must be provided on a different legal basis.

Irrelevant considerations

[40] If, contrary to the clear conclusion which I have reached, Section 8 had been property invoked by the Trust the Trust's decision would in any event require to be quashed for two key reasons. Firstly, although the Trust now avers that it did not take state benefit into account in reaching their determination this runs quite contrary to Ms Hamill's first affidavit which clearly suggests that it was a matter which weighed with the Trust. Secondly, the Trust erroneously concluded that

payment on the basis sought by JF would amount to funding residential care. Again in its most recent affidavit the Trust contends that it did not take that into account but that runs contrary to what was suggested in the first affidavit.

[41] Ms Hamill in her third affidavit sought to escape from the wording of the first affidavit which on any fair interpretation indicated that the latter two considerations were wrongly taken into account by stating:

> "It is the case that at both the leave hearing and in subsequent written argument the issue of (i) the amount of benefits paid; (ii) the components of the benefit; and (iii) the concern about payments being made to cover the same period of time have been raised essentially as matters of argument and context."

It must be said, as counsel ultimately accepted, that the affidavits on both sides in this application contain unnecessary and legally irrelevant material. There was a failure to focus clearly and with reasonable succinctness on the central facts relevant to the issues in the case. The parties unnecessarily expatiated on matters of historical debate between the parties and mixed factual averment with argument. It is not for affidavits to put forward matters of argument for affidavits are not sworn argument. The increasing tendency to use affidavits as a means of presenting argument is to be deprecated.

The impact of the Mental Health (Northern Ireland) Order 1986

[42] Section 8 of the 2002 Act not having yet been amended to reflect the changes made in England and PF having no capacity to consent to direct payments being made to him, if direct payments are to be lawfully made a different route must be followed. Such consent could have been obtained if a controller were appointed on his behalf under Article 101(1) of the Mental Health (Northern Ireland) Order 1986. The controller would be empowered to do such things in relation to the property and affairs of the patient as the court orders, directs or authorises. The powers of the court are set out in Article 98 of the 1986 Order and include the doing of all such things as appear necessary or expedient for the patient's benefit or the benefit of members of his family. Article 99(1) empowers the court to make an order for the exercise of any power including the power to consent vested in the patient. It is thus clear that if the affairs of the patient came under the control of the court the court could authorise direct payment arrangements with the Trust and the making of payments to buy in care from carers. Article 107 of the Order obliges the relevant Health and Social Services Board to notify the Office of Care and Protection when it is satisfied that a person in its care is mentally incapable of managing his affairs; that any of the powers of the court under Article 98 and 99 ought to be exercised and that arrangements on that behalf have not been made. In the present case the Trust once it formed the view that the present situation is justified and called for the implementation of direct payments ought to have brought the matter to the attention of the Board which then

ought to have brought the matter to the attention of the Office of Care and Protection. It would then be a matter for that Office, after making such enquiries as it thinks fit, to take the patient's case into consideration and if it thinks fit arrange for the institution proceedings before the court under Part VIII of the 1986 Order. Under Order 109 Rule 5, if it appears to the court that the property of the patient is less than £5,000 or it is otherwise appropriate to proceed under the Rule, the court may make an order under that Rule, whether or not an application has been made for the appointment of a controller for the patient. An order the Rule is "an order directing an officer of the court or some suitable person named in the order to deal with the patient's property or any part thereof or his affairs in any manner authorised by the Order and specified in the order."

[43] Reading those various provisions together it seems that the proper consent to the arrangements for direct payments under Section 8 could be given. This would enable the Trust to make appropriate payments to enable the patient, with the approval of the court, in accordance with the 1986 Order, to enter into an agreement with JF and GC to pay for care provided.

Relevant considerations for a fresh decision

[44] If appropriate steps were to be taken as outlined the consequence would be that by following two stages the court could, if satisfied, sanction on behalf of the patient terms of a direct payment agreement with the Trust and sanction the remuneration package with the carers. There is not an identity of interest between the patient and the carers who may want to maximise their remuneration and argue for the need to fund a care package at an unsustainably high level. By the same token the Trust may have an interest in minimising the package for reasons of budgetary restraints or to avoid what it considers to be an undesirable precedent.

[45] In the hope of assisting the parties to avoid a further judicial review application and the expense and delay that it would involve the court will set out the guiding principles which would inform any reviewed decision. The starting point is the Trust's duty is to identify and assess the actual needs of the patient which as Lord Nicholls stated in ex parte Barry [1997] AC 584 cannot be assessed without some regard to the cost of providing them. Having assessed the needs it must make arrangements to meet those needs. If the needs are being adequately met by a relative or any of the applicant's own assets it might not be necessary to make arrangements so claimed by the applicant. If there is no other way of meeting the needs as assessed then the Trust has a duty to make the arrangements. These are the so called Barry principles.

[46] In this case the needs of the applicant are considerable. He requires the availability of a high level of adult assistance in his physical care and a high degree of adult supervision throughout the day and on occasion at night. It is clearly in his interests to be cared for at home by JF and GC who are providing excellent care in a safe and secure environment. If this level of care were not provided he would require

residential care which would probably have to involve some elements of nursing care. Clearly a question of reasonable proportionality arises in relation to the Trust's decision as to determining the amount of direct payments justified in the circumstances. Unreasonable and excessive demands by family carers in relation to the cost of providing care, if simply acceded to by the Trust would result in an improper use of state resources.

[47] By the same token if the needs of the applicant point to the great desirability of him being cared for at home by JF and GC (which is the case in this instance) the Trust cannot fix the direct payment at an unfairly low level by recourse to the argument that it is up to the family to provide unfunded the extent of the care required. While Regulation 7 clearly envisages that the employment of relatives will be exceptional such employment is justified if the securing of the services of the relative is considered necessary to meet satisfactorily the prescribed person's needs. In the present case that need has been established and accepted by the Trust.

[48] In determining how the direct payment should be calculated the Trust is entitled to consider whether some of the care could reasonably be provided outside the home by the Trust or agents funded by the Trust. The comparative cost of state residential/nursing care must be a relevant factor for the Trust to take into account when considering the level at which the direct payment should be calculated in relation to the relative carers. A figure significantly in excess of the equivalent cost of state care might properly be considered by the Trust to be an unreasonable use of state resources. The Trust's duty is to ensure that PF's needs are catered for. A view by the Trust that they could be adequately catered for by such state funded care could be a rational one in the circumstances. Furthermore if for example suitable day care is available for periods of time and the Trust properly directing its mind to the suitability and adequacy of that care concludes that such care could meet in part the needs of the patient that would have the effect of reducing the time JF and GC can be expected to spend in meeting of the care needs of PF. The Trust will have a reasonable margin of appreciation in relation to that issue.

[49] In looking at the direct payment package the focus by the Trust has been on a calculation of hours of care to be funded at an hourly rate. Such an approach may fail to take account of the ongoing caring and supervisory responsibilities of the carers outside those hours allowed for. For example, the overall caring responsibilities of the carers do not cease outside those permitted hours or outside the hours when the applicant might reasonably be catered for by Trust agencies such as day care. Thus, for example, care does not cease at weekends and at night. The carers can be expected to respond to the problems of emergencies. At the same time even in the hours of caring which the Trust is willing to fund the carers are not caring for the patient every single moment of the day. He lives in the dynamics of a family environment where other aspects of ordinary life go on. The question for the Trust to determine is what reasonable direct payment package is appropriate bearing in mind that –

(a) JF has reasonably and conscientiously undertaken a full caring responsibility for PF each day of each week and at all times when he is not covered by caring responsibilities undertaken by the Trust; and

(b) the care and responsibilities are undertaken in the home environment where the caring responsibility is undertaken. While it calls for a full commitment JF and GC are free to some extent to lead a family life albeit with severe limitations arising from their commitment to PF.

[50] If the Trust cannot obtain the consent of the patient obtained through the mechanisms of the 1986 Order it may well be that there is another legal basis for meeting the costs of the care. The Trust may be entitled to deal directly with JF and effectively engage JF and/or GC to provide the care and services necessary to meet the needs of the patient in conjunction with the care and services which the Trust can provide and fund outside the home. The court has heard no argument on the legal issues which would arise in that context and it is not called on to determine questions that have not yet arisen. It is to be hoped that the Trust and JF can work out suitable arrangements without the need to litigate further.

The back-dating issue

[51] In relation to the issue of the claim to backdate payment of the additional 21 hours this claim illustrates the problem which arises from the failure to distinguish between the interests of PF and the interests of JF and GC. PF has in fact received exemplary care throughout the relevant period. It is JF's complaint that he and GC were not properly remunerated for that work. PJ has himself suffered no loss and no personal injustice to him flowing from the fact that 21 hours subsequently allowed for was not backdated. He had no contractual rights against the Trust obliging it to pay him a sum for onward payment to JF there being no contract to do so. This is not to say that when the matter is reconsidered the SE Trust might not consider it appropriate to backdate their decision.

Article 8

[52] Similarly there was no breach by the Trust of the Article 8 rights of PF. His right to family life has not been infringed by anything that the Trust has done. If JF asserts that the lack of proper recompense of the services he and GC have provided infringed his Article 8 rights that is not a claim that can be asserted in these proceedings.

Disposal of the application

[53] I will hear counsel on the terms of the relief to be granted in these proceedings having regard to the contents of this judgment.